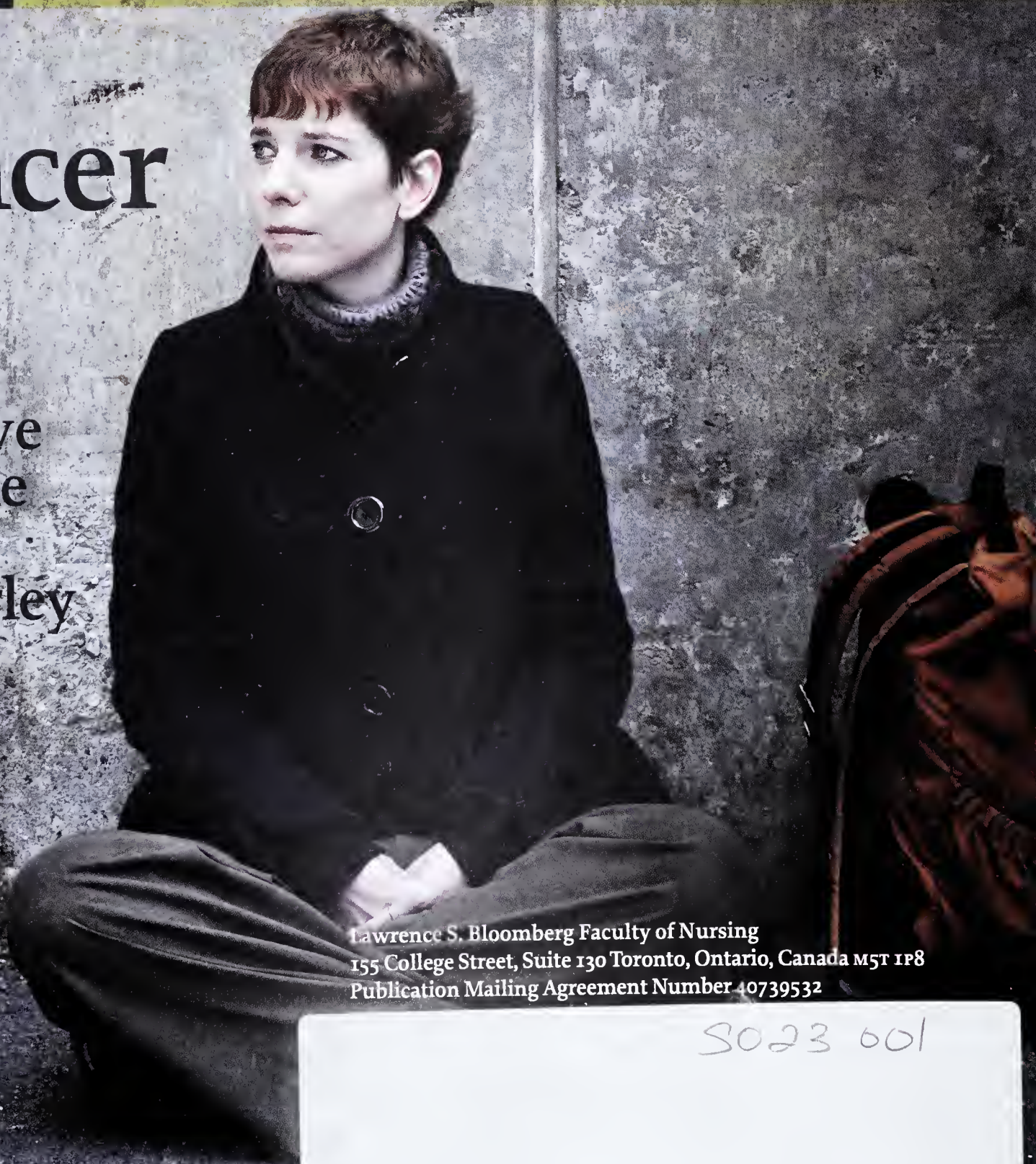


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The Cancer Issue

How do you
provide palliative
homecare for the
homeless?
Nurse Laura Fairley
investigates



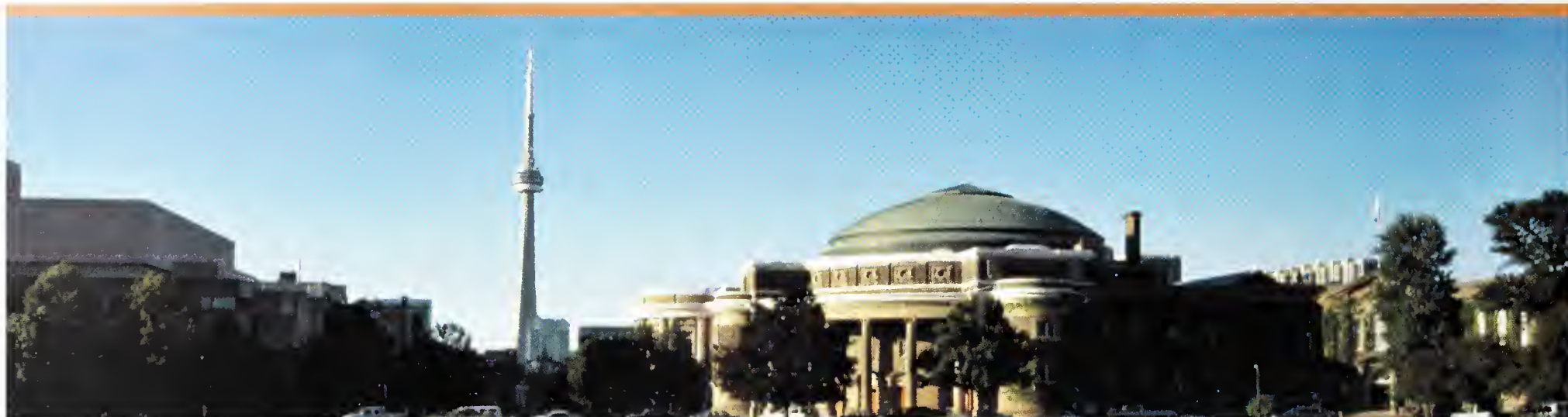
Lawrence S. Bloomberg Faculty of Nursing
155 College Street, Suite 130 Toronto, Ontario, Canada M5T 1P8
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An oncology-nursing seminar course elicits the art of nursing in 'Counterpoint.'

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Hubert Kang
Photographer

Home base: Vancouver **Favourite technological gadget:** “My 1950 Rolleiflex T Camera. Not exactly a toy, though, because I do use it for serious photographic work. It’s my favourite because it’s simple and solid. I love the tactile feeling of turning dials and knobs, looking down the ground glass, and producing a tangible piece of photography.” **Bio:** “I am made in Taiwan, assembled in Canada and reprogrammed in the UK. My philosophy in photography is: ‘You photograph what you are.’ My upbringing had Eastern and Western influences, so I’ve learned to always look at things from varied perspectives and aesthetics. I am attracted to energy, forms, light, and raw emotions. In my photographs, I mix these elements with my life experiences to communicate what I see in this fascinating world.” Kang shot the portrait of alumna Dr. Verna Splane, Dip. Public Health Nursing, 3T9, DSc. 0T7, for our Q&A on page 30. **Chardonnay or Cabernet:** “Cabernet!”



Dr. Mary Jane Esplen
Writer

Home base: Toronto **Greatest passion in life:** “Music and the arts. I am a cocktail pianist, and am currently looking for a lounge job for Friday nights.” **Favourite technological gadget:** “A mixer for baking. I bake 17 different cakes and 22 different pies. I also use it to make skin cream as I used to study chemistry.” **Bio:** Dr. Mary Jane Esplen is a clinician-scientist at University Health Network, an associate professor, Bloomberg Faculty of Nursing, cross-appointed to the department of psychiatry, Faculty of Medicine, University of Toronto. She is the inaugural director of the de Souza Institute, a centre for oncology knowledge transfer based in Toronto. Esplen has a PhD in psychosomatic medicine from the Institute of Medical Sciences, U of T and completed a post-doctorate fellowship in cancer genetics at the Samuel Lunenfeld Research Institute. She has a strong interest in developing measurement tools and interventions for cancer genetic populations and individuals with cancer. She wrote our Opinion piece on page 32. **Chardonnay or Cabernet:** “Cabernet.”

The first edition of *Pulse* is a great read! It is innovative, interesting, scholarly and informative and so beautifully captures the Faculty’s clinical breadth and depth. I am looking forward to the next issue.

Kathleen Arpin
Toronto, Ont.

With tears, tremors and pride, I have just devoured the first issue! Immense congratulations!

Krista Keilty, RN, MN 9T5, APN
Director, Post-Masters NP Diploma
Bloomberg Faculty of Nursing
Toronto, Ont.

You made my story something of admiration and pride. I thank you for that! Many people have shared the same views with me about the article. In fact, I had an interview today; almost everyone had seen the magazine and read “Second chance.” People who once saw me as “disabled” claim to see me in a completely different light, thanks in part to the way you told my story.

Safa Masri, BScN 9T8
Milton, Ont.

The range of articles and announcements in the first issue is topical, informative and commendable. However, I found readability problematic for two reasons: font size and colour combinations selected [...] Thank you in advance for improving readability of *Pulse*. May this publication continue to reflect the valiant and strong heartbeat of the Faculty of Nursing in years to come.

Judith K. Hindle, BScN 7To, MA 8To
Regina, Sask.

Congratulations on this great new venture. It’s well done and really informative. Several familiar faces met me throughout the issue. I look forward to your next edition, and wish you well on this project.

Dr. Margaret F. Munro, RN, BScN 6T3, PhD
Founding Dean, UPEI School of Nursing
Stratford, PEI

I would ask you to consider the financial and environmental costs of this heavy stock, multi-colour publication. To me, it does not seem warranted.

Trish Steele, BScN 7T9
Barrie, Ont.

Spring/Summer 2009

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Volume 2/Number 1 *Pulse* is published twice a year for alumni and friends of the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto. © Copyright 2009. All rights reserved. Please send questions, comments, and letters to the editor to pulse.magazine@utoronto.ca. Letters may be edited for clarity and length. Editorial office T: 416-946-3657, F: 416-978-8222.



Tackling cancer care

By Dean Sioban Nelson, RN PhD

Welcome to our second issue of *Pulse*, the Bloomberg Faculty of Nursing's magazine. Thank you for the wonderful feedback on our first issue; we were delighted at your response. You enjoyed the readability, the human element and the way the importance of nursing came through again and again. You also enjoyed seeing, through the stories of our students, faculty and alumni, the way practice has been evolving and the amazing contribution our community has been making to the health of Canadians. You were delighted at how beautiful the magazine is and some of you were worried at the cost of such a professional production. On that last point, I can say categorically due to the talents and connections of our editor, Lucianna Ciccocioppo, you are getting 'front row seats' at the 'gallery rate!' We will of course continue to monitor expenditure in these difficult times and, by updating our email distribution list, we hope to cut down on the hard copy and mailing costs by building our electronic reader base. To conserve energy and limit costs, I would urge you to complete the insert and return (prepaid) to the Lawrence S. Bloomberg Faculty of Nursing so you can receive our information electronically.

In this edition, we continue our approach of producing themed issues with a focus on cancer and oncology nursing. Before you think the faculty has adopted a disease-based approach to nursing, let me reassure you there are many reasons for cancer following cardiac as the second cab off the rank. Cancer is a leading cause of death among

Canadians and as such deserves a clear priority in our teaching and research efforts. In addition to aligning with national priorities, a focus on cancer allows us to showcase the extraordinary range of vital roles that nurses, and more specifically students and alumni of the Bloomberg Faculty of Nursing, play in our health-care system. From health promotion to prevention and screening, from community care to in-patient management, from counseling the increasing numbers of people with high genetic risk, to the application of cutting-edge therapies, from the care of children to the management of cancer as a chronic disease among the elderly, to palliation and end-of-life care, to survivorship and empowerment—all these fields of practice are wonderfully exemplified in the field of oncology nursing. What is more, these are areas of research and practice that demonstrate the remarkable scope of research being conducted by nursing faculty, alumni and students at the University of Toronto. I am sure you are going to enjoy the second edition of *Pulse*. As always, we're interested in your feedback.

Coming up in our next issue: community nursing. If you know of someone who has a unique story to tell in this field, please inform us. We can't promise to use all your ideas, but we look forward to hearing them. We're also planning a special issue in 2010 for the 90th anniversary of the Bloomberg Faculty of Nursing. Got a great story idea from the last 90 years of nursing? Please forward to pulse.magazine@utoronto.ca.



‘Do we really need all these nurses?’

Time to stop the ‘surge-and-cut’ approach

By Dean Sioban Nelson, RN, PhD

If there’s one thing nurses know, it’s that tough economic times tend to mean cuts to the profession. This has been the pattern over the decades, where nursing from Toronto to Manchester, from Madrid to Sydney, from Los Angeles to Sao Paulo, has all too frequently been the health-care service sector that takes the hardest and deepest cuts when the economy, and our health-care budgets, take a nose dive.

There is an obvious reason for this. Nursing salaries account for a major percentage of health-service budgets. As CEOs and CFOs are driven to reduce spending and create efficiencies, the first question that comes to mind is usually: ‘Do we really need all these nurses?’

This is at one level a legitimate question. The drive to answer it has spawned an entire science that measures workload and efficiency, examines the relationship between number and skill level of nurses on patient outcomes, and analyzes the relationship between staffing profile turnover and burnout. The Lawrence S. Bloomberg Faculty of Nursing, through its nursing research unit, has made this Faculty one of the top sites in the world for health-services research in nursing and health care. This unit was founded in 1990 by Dr. Linda O’Brien Pallas and is now co-led by Dr. Diane Doran, along with colleagues in health-services research such as Dr. Ann Tourangeau and Dr. Linda McGillis Hall. Like-wise Dr. Sean Clarke, the RBC chair in cardiovascular nursing research, has been a major contributor to the field of outcome studies, researching nursing and workforce characteristics and examining their effect on patient outcomes.

But the question ‘Do we really need all these nurses?’ is not only an empirical one that good research can answer. It is also a rhetorical question and as such it reflects a worrying attitude to nursing that has bedevilled the profession for more than a century. Even today, when we finally have the data to show quality nursing staff is strongly correlated with patient outcomes—including mortality—the ability to answer that question remains one of nursing’s great challenges. I would suggest the tradition of seeing nursing as resource to be built up in good times and trimmed back in lean ones comes from the very beginning of professional nursing, and the development of hospitals across the world staffed by nursing students.

For a full three-quarters of the 20th century (and more in many parts of the world), nursing student labour fuelled the engines of the modern hospital. Hospitals hummed with industrious nurses cleaning

and washing patients, bed-making and military order and cleanliness ensuring everyone was combed, tucked and compliant, sitting up for inspection during medical rounds and visiting hours. Behind the scenes reminiscent of the hospital in medieval and early modern times, where nurses wove the linen to make the bedding and robes of the patients, student nurses rolled bandages, mended surgical gloves, sterilized and packaged all the sterile materials and packs, sorted laundry items, stocked and restocked drugs and supplies, cooked special diet meals in ward kitchens, distributed all meals and fed all patients. At the same time the hospital was humming with feminine industry (and they were all women), nurses managed the wards, their patients, the operating room, the hospital budgets and overall operations.

In addition to this, there was clinical work, and it was no less challenging or cutting edge than it is today. Early transfusions involved a team of six nurses managing the two patients, careful handling of the delicate glass equipment and ensuring constant flow to prevent clotting. What is a simple dipstick reading today in the past involved a chemistry kit in the scullery or treatment room. Here nurses boiled urine briefly on a Bunsen burner to assess proteinuria (excess protein), and conducted a battery of other chemical tests (involving Condies Crystals or Fryer’s Balsam) to measure each element. Hypodermic injections involved oil lamp heating of solutions and nurses did a great deal of dispensing work in the everyday course of caring for their patients. Pre-antibiotic era nursing meant lengthy and complex irrigations of wounds and douchings. Nurses also possessed a skill set largely unknown today. Fever nursing was a speciality and the complex pattern of peaks and lows and crises that were the natural and distinctive trajectory of specific fevers required great skill to manage. In fact, typhoid nursing was a sub-speciality all of its own and a good nurse’s ability to manage the fever and prevent the often fatal complication of gut perforation was highly lauded by colleagues and patients alike.

When students graduated from their programs and completed their staff nurse year, they made their way into the few senior roles that existed within the hospital sector or moved into the community, public health and home nursing sectors. In the first half of the 20th century it was in these non-acute domains that experienced nurses held their own. As public health or school nurses, or working in the long lost fields

of industrial nursing and private duty nursing, these experienced and educated nurses were linked to their communities and provided education and leadership from the mother and baby clinic to the factory floor. Back in the hospitals, the priority was often volume rather than quality. High attrition rates were considered a normal part of nursing as young girls were worked hard and long, with poor remuneration and little respect for their contribution to patient care. As one colleague of mine was informed in the 1970s at the 'welcome' address by the director of nursing at an Australian hospital school, 'No-one asked you come and you are free to leave if you don't like it'. This 'take-it-or-leave-it' attitude to staffing has left a heavy legacy on nurses over the years. High burnout, workplace injuries and poor health status have been the norm for hospital-based nurses around the world for far too long.

It also has led to the idea that nurses are in a sense a disposable resource, replaceable and interchangeable like frontline soldiers in early 20th century warfare—a necessary expenditure with supply being the critical element for success. But the military is certainly ahead of the health-care sector in its 21st century realization that soldiers are an investment—and a costly one to replace. Despite clear advances in nursing's position in many parts of the world, including Canada, with each turn of the economic screw nurses feel the vulnerability of the sector and the anxiety that once again we may not have learned the lessons of history. As my colleague and friend, journalist Suzanne Gordon says, "Nurses are not a faucet to turn on when you need them and turn off when you need the budget to balance." It is this kind of thinking that has created desperate shortages in successive waves over the 20th century. Every time we cut nurses, we hit a pipeline. It is not today's nurses we affect but the next 10 years' worth of nurses. In five years time, with normal attrition and the retirement of the boomers, there will inevitably be more panicked calls for more nurses once more—but where will they be? Every time nursing jobs are cut, smart young high school students watch, learn and choose other careers, nursing schools don't fill quotas and have to cut staff or move into graduate programs or other areas, and lose the capacity to take more undergraduate students. Meanwhile, health-service providers cut services (along with nurses) and pressured acute care units, and community providers functioning with fewer nurses and busier services, can't cope with the extra demands of students. So they cut places. It then becomes impossible to increase the number of nursing seats and we create a vicious cycle. Meanwhile, entrepreneurial governments and private providers scour the world for nurses, causing more inequity and suffering in their wake as they contract large numbers of nurses from countries that can ill afford to lose them.

It's inefficient and unethical to continue this surge-and-cut approach to nursing that is so much the norm around the world. But sadly, if there is one thing we must learn from history, it is that we don't learn from history. In the 1930s, the prime role for a well-educated nurse was in the community, in public health and private duty nursing. When the Great Depression hit in 1929, one of the things it swept away was the domestic sector of the economy. People simply did not have the money to pay for private duty nurses. This failure led to great hardship among nurses, but it also led to a major shift in the structures of our health-care system, where finally the middle classes embraced the hospital system as the provider of their health care. Home surgery ceased, home deliveries of babies declined and hospital care became the core of all health care. It is worth reflecting on this outcome. When the cuts of the


If we cut off nurses now, we will feel it for the next decade—and it will be bad

'80s and '90s happened in most parts of the world and in-patient care days dropped dramatically over the following decade, it was to the homecare sector that much of cost burden shifted, to patients and their families directly. The growth of personal support workers (PSWs) and a variety of aides working in homecare and in the community has been to a great extent financed, directly and indirectly, out of the private purse.

What are the implications for health care with today's economic crisis? There is no doubt that despite the widespread pain, the cuts of the '80s or the '90s created enormous efficiencies. There was generally capacity to reduce length of stay without affecting quality or outcomes, there were opportunities to advance ambulatory care and important opportunities to be seized in the support of chronic illness at home. On the other hand, the scenario facing us today is that we have 'lean and mean' health-care systems with virtually no 'fat' to trim, the homecare sector is overwhelmed by increased service demand without corresponding increased funding, and the private capacity of citizens to fill in the gaps through PSW employment or other private means has been drastically reduced. Meanwhile, the rise in chronic illness that is accompanying the demographic shift, and the gloomy retirement projections of our RN workforce, makes this a critical juncture for the future of our health-care system's capacity to deliver care over the next 20 years. If we cut off nurses now, we will feel it for the next decade—and it will be bad.

Once again we face the critical question: 'Do we really need all these nurses?' We do. We need new graduates developing their skills and knowledge in a safe and supportive environment so they do not burn out and leave. We need advanced practice nurses bringing creative and cost-effective solutions to complex system problems. We need nurse practitioners to provide access and keep costs down to the great number of people the system currently fails. We need them to prevent illness, manage chronic disease and to keep people well and safe in the community. We need them to track us through the highly dangerous space of the acute inpatient sector and ensure that we avoid life-threatening complications, are well informed and educated about our treatment and its consequences, and go home in the best position possible to undertake self-management of chronic conditions. To cut nurses is to cut the system's capacity to do this now and into the future. It is in everyone's interest to make sure our decision-makers understand this and are held accountable for the consequences of their actions. As members of the profession and members of the public, it is our job to ensure this. ♣♣

Read an abridged version of this article—and the numerous comments it elicited—in the Toronto Star's Opinion section: www.thestar.com/article/599226.



Dr. Kelly Metcalfe counsels women at high risk of developing breast and ovarian cancer. She talks to them about preventative options. She helps them make the

Ultimate decision

By Lucianna Ciccocioppo

Imagine being told you have an 80 per cent chance of developing breast cancer probably by the time you reach 50. What would you do? How many questions and fears are now running through your mind in this hypothetical scenario?

For some women, it's not a hypothetical but a very real situation. It's a conversation they have with nursing professor Dr. Kelly Metcalfe, RN, PhD '02, at her clinic at Women's College Hospital in Toronto. She meets with women who have undergone genetic testing for mutations in the BRCA1 or 2 genes, which indicate an 80 per cent risk of developing breast cancer and 50 per cent risk for ovarian cancer. By comparison, the average woman has a 10 per cent risk of developing breast cancer, and one per cent risk of getting ovarian cancer.

Metcalfe's goal is to prevent women at high risk from ever developing the disease. The associate professor at the Bloomberg Faculty of Nursing and adjunct scientist at Women's College Research Institute is an internationally renowned scholar on the prevention of breast cancer. Metcalfe counsels women about their options. Many struggle with the weight of their ensuing emotions, she says.

"In my research, I found that women had a really hard time making a decision. We're asking young women generally in their thirties and forties to think about removing their breasts and think about removing their ovaries as a preventative option. For some it's an easy decision, but for some women it isn't." The important thing, says Metcalfe, is that the women decide to do something.

That's why she developed an innovative "decision aid," a brochure-like information chart of cancer preventative options that walks a woman through the myriad treatments and side effects she needs to consider before deciding what is best for her. In addition to surgery, options include medications and an increase in MRI screening, now available in clinical practice. The decision aid helps women cut through the dizzying facts and figures and decide what is most important for them: reducing the cancer risk or maintaining the same body image?

"We have been able to reduce the decisional conflict significantly," says Metcalfe, "so women feel much more confident in the decision they're making about cancer prevention. And that's what we really want to impact. We don't want them to change their decision necessarily, but feel confident in their decision." She hopes to one day see the decision aid as part of standard genetic counseling everywhere.

A pilot test of the aid enabled funding by the Canadian Breast Cancer Research Alliance for a large randomized control trial which looked at its impact compared to standard genetic counseling. Initial pilot test results were positive and suggested women were making decisions about cancer prevention options, when previously they were not. It means fewer women will develop cancer and/or die of breast cancer, says Metcalfe.

"There's no right or wrong answer," she says. Still, Metcalfe is curious about the great variances in uptake of the various options, across Canada and in other countries, as her studies have shown. "In Quebec, nobody does anything [after counseling], whereas in BC, more than half of the women have prophylactic mastectomies. In France, nobody removes anything, but in the Netherlands, everybody has everything removed. We don't understand why." Her next project, funded by CIHR, is to investigate the decisions Canadian women make and why.

Metcalfe brings a unique perspective to the issue, given her clinical nursing skills combined with research expertise in genetics. "It's not just about presenting them with the pros and cons. Medically, I'm very aware of the psychosocial implications of all the preventative

The average person doesn't understand what it's like to grow up surrounded by breast cancer

procedures which, for the majority of women, is what they struggle with the most. It's not about 'How am I going to feel physically after this treatment?' but 'How am I going to feel psychologically?'"

The average person doesn't understand what it's like to grow up surrounded by breast cancer and all the angst and fears that accompany the disease, says Metcalfe. For women who have tested positive for the gene, the median age of onset is the mid-40s, and typically the cancer is aggressive. They may have young children and careers to consider. "They're going to do whatever it takes to reduce their risk of breast cancer, and the only answer to that is prophylactic mastectomy; the risk is almost zero."

She thinks it's more accepted as a preventative measure nowadays, a far cry from the crank phone calls she used to get about "how barbaric and crazy" elective removal of the breasts was, when genetic testing first began in clinics in 1996 and Metcalfe wanted to hear from women who had the surgery for her research. About 25 per cent of Canadian women will opt for the prophylactic mastectomy, and almost 70 per cent will remove their ovaries as well.

As someone who watched her mother succumb to breast cancer, Metcalfe wants to ensure other women don't die from the disease "when they don't have to. We've identified these high-risk women and we need to do something about it." Her work attracts letters of gratitude and support from around the world, such as this one:

"I recently received your article via a breast cancer e-bulletin list in Australia. I am a BRCA2 carrier and physician. I discovered my status 18 months ago and have since undergone both oophorectomy [removal of the ovaries] and bilateral mastectomy. I have never had cancer, but almost every other woman in my family has died of breast cancer and my younger sister has been treated.

In Australia I do not have access to regular breast MRI and [anti-cancer drug] Tamoxifen was not available for use prophylactically in high risk women when I was diagnosed. It seemed obvious to me, though horribly difficult to do, that these surgeries were the only sensible choice in my situation. I have seen enough cancer to know what I am up against.

However, though my genetic service mentioned these options to me, the information provided was little more than a paragraph outlining the benefits and the fact that most people who undertook these options were content with their decisions. Beyond that, the research and planning of my surgery options was all up to me... I was angry about the lack of support provided... If women are not supported to understand their options and make these decisions and to live with the consequences then of course the uptake rates will be low. These

Decisions for our daughters

It's called the "common flu" of sexually transmitted diseases, and 75 percent of people will get it at least once in their lifetime. Human papillomavirus causes genital warts and cervical dysplasia, the earliest form of pre-cancerous lesions recognizable in a Pap smear. But persistent high risk HPV infection can lead to much worse: cervical cancer, the second-leading cause of cancer in women worldwide.

Ontario funds HPV vaccination programs in schools for girls in Grade 8. But only about 50 per cent of schoolgirls opted to receive the vaccine in 2007 when it began. It was a hot topic in the media, given the age of its recipients, and parental fears it would promote promiscuity. The vaccination rate in Atlantic Canada, however, was higher: 80 per cent.

This raised questions for PhD student Catriona Buick Roberts, MN OT8. She wants to find out why the uptake rate in Ontario is so much lower. Her doctoral research, under the supervision of Dr. Kelly Metcalfe, will investigate attitudes and decision-making about HPV and its vaccine. "Are we getting the right information out to the right people?" asks Roberts. "What are their attitudes and beliefs about HPV and the vaccine? We'd like to give people information so they can make informed choices. Families need to make decisions that are right for them," she says.

The vaccine will have a large effect on pre-cancerous lesions on the cervix and genital area reducing not only the burden of cancer but also HPV and HPV-related symptoms. Hopefully, fewer procedures like colposcopy (diagnostic follow-up for abnormal Pap smears) will be required, says Roberts, saving resources and reducing anxieties for people. While we won't see the impact of the vaccine until these girls reach their forties, Roberts says her research results will help focus where better resources are required to get the word out about the preventative vaccine. "It's a unique way for a nurse to get involved in preventing cancer right from the start."

And yes, if Roberts had a daughter, she would have her vaccinated. ♣♣

are very hard decisions to make and the support required is significant and is not routinely provided here... This is such an interesting and difficult arena. Thanks for your work."

—Name withheld

It's not simply about preventing someone from going down the long, tortuous and costly road of cancer treatment, typically one year of radiation and chemotherapies. It's about thinking ahead to the next generation carrying the mutated BRCA1 and 2 genes and what their best options will be in 30 years' time.

It's about pushing through with breakthrough research, such as Metcalfe's, to fuel the growing global knowledge on genetic predisposition to disease, so maybe one day, there will be one less difficult decision for someone to make. ♣♣

Motivated into action: Gateways project co-investigators Nancy Barry and Linda Muraca are streamlining cancer screening for women with disabilities.

Banishing barriers

When women with mobility disabilities told Laura Muraca, MN oT7, about their frustrating challenges trying to get cancer screening, she was shocked. That's how project 'Gateways' was launched

By Lucianna Ciccocioppo

Linda Muraca, RN, MN oT7 expected the usual questions and concerns from women during one of her AstraZeneca Breast Health presentations that was held at the Centre for Independent Living in Toronto. What she didn't expect were the frustrating stories of deterrence to screening from these women with disabilities.

"It was very disconcerting," said the nurse clinician from Mount Sinai's Marvelle Koffler Breast Centre. "They told me, 'Well, I'd love to go for screening, but no one could get me on the table, or the mammogram machine couldn't go down,'" She was shocked, but thought it was an isolated case of things gone wrong.

In a subsequent presentation at CILT, "the stories were even more detailed," says Muraca. She thought: "We need to do something; someone needs to be informed about this." Disability advocate Nancy Barry, BA 9T5, completely agreed. CILT's peer support and volunteer coordinator, who has cerebral palsy, says her first mammogram was painful and humiliating. "The technician had never screened someone with a disability. She had no idea how to 'handle' me." It was Barry who had invited Muraca to speak. The two were quickly motivated into action.

Backed with a grant from the Canadian Cancer Society, support from CILT and Bloomberg Faculty of Nursing qualitative research expert Dr. Jan Angus, RN, BScN 7T8, PhD oT1, Muraca led a needs-assessment project as part of her final MN practicum. She and Barry ensured women with mobility disabilities were part of the research questions, not just part of the research. "It made the research richer and appropriate," says Muraca.

Aptly named "Gateways to Cancer Screening," the project ran five focus groups, four in downtown Toronto and one in Peel region, for a diversity mix. Women with mobility and sensory disabilities, women from various multicultural groups and from low-income households were consulted. The methodology was participatory action research, selected to guarantee knowledge transfer from the Gateways Project to cancer-screening services and health-service providers, and

to foster practice change and make it more inclusive.

"This was extremely important for the women because many of them had participated in other projects where the final report sat on a dusty shelf and nothing changed," says Muraca. With a comprehensive background in oncology nursing, an understanding of patient experiences, and an expertise in community health promotion, she wasn't about to let that happen.

The conclusions showed there was work to be done. The biggest deterrence to screening for women with disabilities was not what you think—architectural barriers. Repeatedly, participants placed their bodily experiences, their vulnerabilities and embarrassments at the top of their list of frustrations.

"I know that at my doctor's they do have a bed that can be lowered. But I transfer myself... I can see that if I couldn't do it myself, they wouldn't be able to do it for me. It would mean having to ask someone else to go with me. And who wants to have someone else in the room when you're having a Paps smear?"

"These women are unbelievable self-advocates for their health; they do a ton of work to avoid coming down to a hospital... because it's complicated," says Muraca. The number of steps and potential constraints are numerous: an accessible bus or taxi booking, an appointment that starts and finishes on time, accessible exam tables, accessible change rooms, accessible washrooms, and most importantly, an attendant to help these women in and out of their wheelchairs. There usually isn't one, which means waiting for another available technician to assist, which means waiting for another bus booking, since the scheduled pick-up will be missed. It's a frustrating chain of events that can escalate and add to screening anxieties. It means women with disabilities are unlikely to return for another screening.

"These are important things to find out because these women have the same risks of developing cancers as the rest of us but getting treatment for them would be more difficult," says Muraca. She talks of a disabled woman whose mother died from colorectal cancer, and she





too died of it. She wasn't screened regularly, says Muraca. "It could have been for a number of reasons, but I wonder—was it the ease of getting checked all the time? Was it missed? Are these women going to present at later stages because of these issues?"

"I've had a colonoscopy three times. They gave me a bottle (which weighed more than I do!) and I know there are other delivery systems that don't require this endless drinking. My father was given three little containers to drink and it worked on him. My suggestion is, because it's difficult to get off from a wheelchair, that doctors be more informed on the elimination processes available."

Muraca wants to streamline the screening process to see disabled women in as frequently as other women for regular checks. "If we're picking up problems earlier, it will save health-care resources down the road, and save on human suffering too." More importantly, health-care providers and clinical staff need disability training, so they can complement the accessible exam tables, screening technology and on-site attendant care. She wants to make screening accessibility a major issue like it was for restaurants and other public venues.

The Gateways Project landed her a 2008 Masters Student Award of Excellence from the Council of Ontario University Programs in Nursing. Her co-investigator Barry won an Access Award from the City of Toronto. The next stage is to hear from the health-care side on screening women with disabilities, create DVDs depicting the troubling scenarios the women described to help train health-care providers, and then evaluate pre- and post-DVD to see what practice changes occurred.

"Some women talked about positive experiences: polite receptionists who asked if any special accommodations were required... at Mount Sinai if you tell the receptionist you are disabled, an extra half hour is booked for you, and you get an extra technician."

Something as simple as better communication is key, says Muraca. "We need to be asking, and they need to be telling." Just one way to banish another barrier. ♣



Banishing barriers abroad

A study mapping access to preventative health care in Canada is making its way around the globe as a successful method to help banish barriers to cancer screening for women.

Bloomberg nursing professor Dr. Jan Angus interviewed 35 Canadians from diverse backgrounds about how they were diagnosed and their activities involved in seeking treatment. She then made maps of what had occurred.

Turns out, it wasn't always as simple as going from point 'A' to point 'B.'

"Many women had very effective access to health care, but some women had quite tortuous pathways," says Angus. "It may have taken them several months to connect with a health-care provider, or the health professional didn't think they had cancer and did not refer the patient. Some women had very busy lives and did not keep pressing the issue. There were many factors at play."

These preliminary findings were published in a Brazilian journal, *Texto Contexto*, and translated into Portuguese and Spanish. The study piqued the interest of a nurse researcher in Spain, says Angus, and Clara Juando is currently replicating the project in Barcelona, a city with a large immigrant population.

"Part of my study found new immigrants to Canada have more difficulty accessing health-care providers, for multiple reasons: they may not know where to go for help or they are still not eligible for provincial health insurance (a three month wait); they may have language issues; or may not have the same level of breast cancer awareness that the same population already residing here may have," says Angus.

But the international connections don't stop in Spain. The same study is going on in Nicaragua, where medical professor Dr. Clara González is investigating barriers to cervical cancer screening, thanks to the collaborative efforts of Bloomberg nursing professor Dr. Denise Gastaldo and Dr. Lawrence Paszat, of the Faculty of Medicine.

Preliminary data should be available early spring, says Gastaldo. "We'll take the results to the ministry of health in Nicaragua and to municipal governments to make women's health a priority, and start discussions with policy-makers and politicians about what the best alternatives are to change these patterns." ♣



Comfort in the face of discomfort

Bloomberg Faculty of Nursing researchers and alumni are breaking new ground in the growing field of symptom management. For cancer patients, it can't come soon enough

By Lucianna Ciccocioppo

For those living with cancer, the sting of treatment effects can add to their pain, anxieties and fears. Nausea, vomiting, fatigue and breathlessness are part of the bewildering cancer journey some patients have to endure. Some take comfort in their Internet blogs. Shin Na (shinscancerblog.blogspot.com) from Singapore writes: "I'm having the worst breathing problems I've had so far and can't spend time with the kids for fear of having an anxiety attack that would scare them." As her cancer progresses, her friend and "chemo buddy" takes over the writing: "She mentioned anxiety and panic attacks in her last blog. These continue. In fact, her breathlessness now has turned in to a feeling of suffocation. This in turn creates anxiety, adding further to the suffocation. She feels claustrophobic when this circle begins."

It's painful to read; imagine suffering through it, or watching a loved one experience it.

But there is hope. New research at the Bloomberg Faculty of Nursing is investigating ways of minimizing such distress by first understanding exactly what the patients are experiencing—and not just from a biological perspective.

"There's very little understanding of all the other psychosocial and contextual life circumstances that actually play into the patient experience of cancer," says Dr. Doris Howell, RN, MScN 8T3, PhD oT3. "People who have a sense of personal control may actually perceive a symptom differently," says Howell, RBC chair in oncology nursing research at University of Toronto and University Health Network. Her research focuses on understanding how patients process symptoms, and has found psychological variables, such as depression and anxiety, can influence the severity of one's symptoms.

While most of the current interventions for symptom management are pharmacologically based, Howell says it's time to look at better self-management techniques of symptom relief, to give patients a sense of control once again. "Most times, patients don't take on self-management because they don't feel there's anything they can do about the symptoms, such as fatigue. So they feel very helpless about their fatigue right from the start."

Fatigue affects about 90 per cent of cancer patients in treatment. In fact, studies have shown exercise, proper diet and prioritizing daily activities are effective ways of managing fatigue and energy levels. "It's much more than giving patients a self-care educational package, and saying 'Here's something that might work.' We don't give them a lot of tools with tips about how to manage their symptoms, and how to actually integrate these tips in their day-to-day life at home. How do you organize new pain medications, now that the patient is up every four hours at night, and integrate this into a new way of living with managing a symptom?" Howell likens it to learning to live with a

chronic illness, for example diabetes or arthritis. "You have to learn new ways of moving, exercising and functioning. It's a new lifestyle integration around a cancer diagnosis and the symptoms related to that."

Symptoms such as dyspnea, or shortness of breath, have significant meaning for lung cancer patients who interpret this problem as a sign of how advanced their disease is, says Howell. And it triggers all the emotional feelings related to it, such as cancer being a potentially life-threatening illness, which prompts more fear, which could influence the severity of the problem and worsen the symptom. Adds Howell: "What we're trying to do in our research is understand what those trigger factors are so we can line up supportive care and interventions."

We don't have to look too far for a Bloomberg Faculty of Nursing connection to an intervention that is turning heads across the province. Over at Credit Valley Hospital in Mississauga, clinical nurse specialist Cathy Kiteley, RN, MScN 9T7 worked on an evidence-based intervention in partnership with Cancer Care Ontario, developing a program of assessment and management of dyspnea, which included an educational toolkit for nurses. New lung cancer patients make up the majority at the Carlo Fidani Peel Regional Cancer Palliative Care Clinic and breathlessness was identified as a significant symptom to manage, after fatigue, says Kiteley. "We knew right there that, although it's not the number one symptom on the Edmonton symptom assessment system (ESAS), it's a high priority because it's often an underreported symptom as well as under-assessed symptom, that can be as difficult or perhaps more distressing than the pain," she adds.

The program was promoted to every nursing agency in the Mississauga, Halton and central west health regions, and a nurse leader took charge to continue rolling out the intervention, explains Kiteley. The nursing toolkit includes a guideline to assess if medical intervention is needed, and advice on breathing and relaxation techniques to help reduce the breathlessness symptoms. What was missing was the patient's tip sheet—and that's what Irina Nistor, RN, MN (ACNP) oT9 created. During her clinical placement with Kiteley, Nistor, now at Mount Sinai Hospital, produced a brochure aid dealing with managing breathlessness around daily activities, including rest breaks. It also taught breathing exercises. "I know how scary it can be for patients when they're having difficulty breathing. I can imagine being in the community and not having any information about what to expect in this type of situation or how to manage it," she says.

There's a whole field of work unfolding in this area of interventions, says Dr. Margaret Fitch, RN, MScN 7T7, PhD 8T6. The associate professor (status only) at the Bloomberg Faculty of Nursing and associate scientist at Sunnybrook Research Institute researches the challenges not

only of symptom management but also the patient's whole experience with cancer.

Fitch has developed a measurement tool called the fatigue pictogram. "It's a clinically useful tool for a practitioner to identify and monitor people struggling with fatigue. Cancer patients can tell you how much fatigue they are experiencing and how much it interferes with their lives." The rating scale substitutes numbers with pictures and colours, which makes it relevant for people whose first language may not be English, or who find a numbered scale difficult to apply. Used at Sunnybrook Hospital in Toronto, Fitch says a colleague in Brazil asked for a copy and had it translated into Portuguese for use there. Through her leadership role in the Cancer Action Journey, Fitch hopes to foster changes in the cancer system to make it more "person-focused. At the moment, it's predominantly a 'tumour-focused' system," she says. "What we need is a little bit of balance. Cancer is more than a

that role, which allows us to manage more patients more productively. And keep them out of the hospital. The APN can do consults in our unit and adjust medications over the phone. Without that, some patients would end up in the emergency department for unmanaged symptoms." Sauls says the breathlessness intervention program has become a model for other settings in Ontario, through the Cancer Care Ontario network. "We've had positive reactions from other places."

For Credit Valley Hospital nurse Cathy Kiteley, the success of the program is two-fold. "I had one patient tell me 'This saved my life!' But it also really identifies the nurse as a knowledge worker, not a task-based individual, and as someone who cognitively uses the literature to help assess, plan, manage, intervene and evaluate care." Nobody wants to spend any more time in a cancer centre than they have to, says Kiteley, and this nurse-led intervention gives patients control in their own home. While Sauls says they don't have the hard data to measure

Cancer is more than a physical disease. It has emotional, social, psychological and spiritual impacts and consequences. If we don't pay attention to those as well, then it can be a very difficult experience for people

physical disease. It has emotional, social, psychological and spiritual impacts and consequences. If we don't pay attention to those as well, then it can be a very difficult experience for people."

The same goes for health-care providers as well. That's where the palliative care and symptom management consultation service (www.ppsmctoronto.com) comes into play. It's a program that exists across the province but was only recently launched in Toronto, where nurse practitioner Cindy Shobbrook, RN (EC), MN oTo, provides one-on-one consultation to health-care providers. She's the 'go-to' nurse for practitioners struggling with complex pain situations, such as medication titrations and conversions, or resource searches. "It can be an information exchange on best practices, a mentoring moment," says Shobbrook. "It can also be more challenging, such as working with a nurse on multifaceted cancer cases, those with complications."

She's contacted regularly for consults by long-term care nurses, agencies and homecare nurses. "A hospice nurse from Perram House asked for support for patients who were high risk for substance abuse—how to respect their autonomy and still support them. Another nurse in an acute care setting called about relieving constipation," says Shobbrook, who advises physicians and allied health professionals as well. "You can hear their sigh of relief when they get the assistance to address real problems in real time for their patients." And with the increasing number of cancer patients and survivors living with the after-effects of treatment, there's a growing need for her advanced nursing skills and expertise in this unique service.

That's because advanced practice nurses have the time and clinical abilities to do a better job at the holistic assessment of each patient, says Dr. Robert Sauls, palliative care program director at Credit Valley Hospital. "Our program is more productive because we have an APN in

the impact, the 10-point ESAS scores of patients suffering from breathlessness fell to '2', down from '3-4', over the same time period last year, when the intervention program was rolled out.

All this means a better quality of life for patients, and an improved, efficient health-care system for society. Emergency admissions are reduced, as are unnecessary or inappropriate dispensation of drugs. Says nursing professor (status only) Doris Howell: "If we know how to target the symptom experience problem more effectively, then we're not going to keep trying different agents, when it's not the pharmaceutical agent that's the issue. It's a supportive care issue."

This support is crucial. Patients have told Howell in an earlier study that having an oncology nurse who understood their cancer experience and supported them in their symptom management was a "transformative" moment for them, since they no longer felt "lost" in their cancer journey but could put their coping techniques to work.

Howell's expertise will help shape practice change for clinicians to be more comprehensive in their assessment of symptoms, and more inclusive in all the psychosocial factors surrounding these issues. Her research will help pinpoint realistic goals to deliver in high volume cancer clinics. "Nurses will play an increasingly vital role in educating patients and preparing them for self-management of their symptoms," she says.

Half a world away, breathlessness is no longer an issue for Shin Na. She lost her fight with cancer on Jan. 29, 2009.

But for the increasing number of cancer patients and survivors, their battle continues, empowered more and more each day with this innovative and critical new knowledge in symptom self-management.

Researchers and alumni from the Bloomberg Faculty of Nursing take comfort in that. ♣♣



Kira Goodman's *The Only Way Out is Through*: A second-year nursing student's concerns about the uncomfortable process of bone marrow aspiration, used to determine if certain chemotherapies are successful in some hematology disorders.

Counterpoint

By Lucianna Ciccocioppo

It's to make students think about the practice of nursing in a completely different way: through the arts. Senior lecturer, Dr. Francine Wynn, RN, BA 7T7, MA 8T2 engages students to think about their profession but not within the usual intellectual and cognitive frameworks. For this second-year seminar course, students are working with materials, dealing with form, colour and rhythm in ways that reflect their practice. The course is clinically focused and deals with persistent illness across various medical settings. Other teachers are also doing a project approach for this course. Wynn teaches in the oncology section, focusing on the interpersonal process of caring for people undergoing active cancer treatment. Students discuss suffering and embodiment—how suffering is experienced in the body, how patients and their families cope, and how challenging it is to work in such an environment.

Then, they make an art piece.

"Some are very anxious, and not keen," says Wynn "because they don't think they know how to produce art. The focus is not on artistic quality, but rather what they can capture through the arts that cannot be captured in words or in technical language." Students have painted, quilted, composed music and poetry, made sculptures and choreographed dance. The artworks are presented to the class and a discussion follows. Wynn says it allows students from all backgrounds to describe clinical experience in its particularity. It's also changed her understanding of students.

"One of the pressures of new graduates is to maintain their understanding of the meaning and effects of treatment for their patients once they are in a clinical setting. I think this will be a memory piece for them, something that will remind them what was important when they get caught in the speed of practice and the 'busy-ness' of technical work. It might offer them a counterpoint." ♣♣

Doctoral dream team

Bloomberg graduate students are at the forefront of nursing scholarship with their innovative studies in cancer care. And people are paying attention

By Lucianna Ciccocioppo

Clearing up the 'fog'

Samantha Mayo, RN, BScN oT4, MN oT6, hopes to reduce stress and anxiety among recipients of bone marrow transplants when they start to worry about misplacing their keys one too many times, can't concentrate on reading, or even forget to pick up their children from school.

"We know there are neuropsychological tests that measure functions and tasks; what we don't know is the impact of treatment on day-to-day activities," says Mayo. And after hearing these concerns from her patients at Princess Margaret Hospital, Mayo decided to delve further. Her doctoral research will survey people after bone marrow transplant treatment of blood cancers and disorders, such as leukemia and aplastic anemia. These transplants are accompanied by high doses of chemotherapy, radiation and immuno-suppressants. Patients complain of "being in a fog," says Mayo, and worry about life after treatment, particularly handling responsibilities at home or at work.

"By understanding what contributes to these issues patients are experiencing on a daily basis, we can try to address them, and hopefully alleviate their concerns by creating some interventions for them," says Mayo. Patients gain back a sense of control in their life when their concerns are validated, adds Mayo. The new knowledge from her research will help create resources required to help patients get on with their lives. It's an important issue, as cancer survivor rates increase and patients strive for an optimal quality of life.

Mayo says it's unclear when these symptoms first appear, whether they are immediate or part of the late effects. "So we need to find out when interventions should start," she says. There are several interventions for people with significant memory impairments, but not for those with subtle issues. "That's where we need more general interventions because these minor, cognitive changes can be very distressing as well."

The deconstruction of decision-making

It's a far cry from finance, but **Shan Mohammed, RN, BScN oT4, MN oT6** wouldn't have it any other way. After five years in investment banking, Mohammed turned to oncology nursing. "Being a nurse is very meaningful for me; it's a continuation of my mother's spirit. She was a nurse, and cancer is part of my family experience."

Mohammed is investigating the complexities of decision-making among cancer patients with advanced illness. "We don't know a lot about this issue from the patients' perspective," he says. "How do some patients come to the decision to continue with certain treatments when they're very ill? Is it how we structure our care, or are there other factors involved?"

He hopes his doctoral project will shed new light on the ongoing discussion about end-of-life treatment and how to balance patient choice with responsible care. "I want my research to contribute to the

wider body of knowledge on this issue, and examine how patients make sense of their care. There are very good reasons why very ill patients choose to continue treatment," says Mohammed.

He'll explore the options and alternatives to treatment, the role of supportive care or counseling, and the impact the patients' family has on decision-making. Mohammed says his clinical expertise in oncology care positions him to conduct his research from a unique perspective.

"Nursing and supporting patients on a daily basis informs my research. I appreciate what the patients are actually experiencing, what their symptoms and fears are. It's a complex issue, and I want to understand the complexities." He would like physicians, nurses and health-care practitioners, in addition to policymakers, patient groups and advocacy groups to understand the issue better as well, and hopes to disseminate his findings broadly to initiate a more effective process of offering treatment at the very end of the cancer journey.

The costs of cancer

When a family hears their child has cancer, a myriad of emotions, coupled with a dizzying amount of new information, can overwhelm them. But there's one more thing **Argerie Tsimicalis, PhD (C)** would like them to think about: the economic impact. In her doctoral study of the costs incurred by families with children with cancer, Tsimicalis found families eager to talk, contrary to previously raised concerns that it was an inappropriate topic to broach after a diagnosis. "But I had a very high participation rate in my study, which suggests this is appropriate to talk about," she says. Families need to know that a child's cancer diagnosis will cost them "X" amount of dollars per month, "so they are better informed, and prepared about their cancer experience, and hopefully reduce some of the anxieties," she says.

Tsimicalis tracked 111 families at Sick Kids' Hospital in Toronto and McMaster Children's Hospital in Hamilton on their expenditures in and out of hospital, such as meals, mileage, parking, medications, supplies, childcare for siblings at home, and lost time at work or school. She's currently writing her thesis but can say the costs incurred do add to stress levels.

"What happens to benefit plans if parents lose their jobs due to lost time? Who pays the rent or mortgage?" It's a significant issue, she says, one that's not visible in the public realm—but should be. "We need to engage the public and ask ourselves how do we as a society support a child and family with cancer?"

She'd like to effect change at the policy level and argues for a universal prescription plan. She'd also like to see increased resources for families after diagnosis, such as access to a financial counselor, to nip potential problems before they deteriorate. "We need to support families so they can be where they want to be—at their child's bedside," says Tsimicalis.



Shan Mohammed, RN, BScN oT4, MN oT6

Samantha Mayo, RN, BScN oT4, MN oT6

Argerie Tsimicalis, PhD (C)



Doris Leung, RN, MN 9T9, PhD (C)

Lisa Seto, RN, MN oT5

Prisco Salvador, RN

Tackling taboos

Lisa Seto, RN, MN is researching end-of-life care and experiences in Chinese-Canadian families—not an easy subject matter to tackle in a cultural group thought to be superstitious about death.

“It can be a taboo topic; if you talk about death, you’re reinforcing bad luck,” says Seto. But when she did some field work with a nurse colleague from Princess Margaret Hospital in Toronto, Seto found this may not necessarily be the case. She went into the homes of Chinese patients with advanced cancer and discovered their families were open to discussion.

“I went to two homes, one of a recent immigrant, the other who had been here 20 years. So possibly we are stereotyping. Instead of assuming Asians don’t want to talk about death, we might discover better ways to approach the topic that would be more sensitive and allow people to discuss their experiences,” say Seto.

Her doctoral project will focus on the meanings of “home” for the participants and outside homecare providers, and “how this meaning shifts when it becomes a place of death.” Through interviews and observations, Seto will document and analyze daily activities and “how the meaning of home can structure, constrain or facilitate their abilities to negotiate end-of-life care. I hope the study will really speak to individual experiences and the diversity within cultural groups—how different experiences of migration, settlement, and socio-economic status play into a sense of belonging in their own home, and in this country.”

New knowledge on current nursing practice and assumptions about cultural groups can impact care, says Seto. She’d like to increase awareness among health-care providers during end-of-life discussions with immigrant families, and point nurses in the right direction for appropriate resources in order to provide more effective palliative care in the home for these groups.

The end-of-life discussion

When **Doris Leung, RN, MN 9T9, PhD (C)** was first exposed to death as a young nurse at Toronto General Hospital, she found it to be a stressful experience. “I wasn’t taught how to deal with death and dying,” says Leung. But today, the PhD candidate will soon be lecturing on this issue at the Bloomberg Faculty of Nursing. That’s because what she experienced long ago was still occurring among nurses in 2003, a year she faced several deaths in her extended family. She saw nurses struggling with death and dying, but this time from a family’s perspective.

“I thought: this is a real problem. Nurses are uncomfortable about this issue, and didn’t know quite how to support families during this time.” She decided to investigate and started her PhD researching nurses working in bone marrow transplant services, a patient population with significant risk of death and complications. “These nurses have experienced the complexities of providing care for transplant patients, where, at any given moment, patients may be ‘teetering on death’s door,’” says Leung. She found the nurses were struggling with high stress and uncertainties about the ethics of the right course of action for their patients. Nurses were struggling when patients began confiding in them, says Leung, and sought advice about another bone marrow transplant. “This is one option that nurses might disagree is best for particular patients at that moment. And, as a result, nurses may not know how to respond,” says Leung. “This kind of patient experience hasn’t been examined before, and it does cause a lot of distress for nurses.”

One research project will focus on the meanings of ‘home,’ and how this shifts when it becomes a place of death

Leung wants communication skills about death and dying to be taught in schools for all front-line health-care providers. She’d like to see better support in place for nurses, such as improved debriefing skills, to engage in these issues and improve the transition from acute to palliative care when patients are in distress. When health-care providers communicate better with patients and their families, there is less stress all around, and a seamless continuity of end-of-life care with no delays or possible emergency readmissions, says Leung.

Back to basics with baking soda

In his 18 years of oncology nursing, PhD student **Prisco Salvador, RN** has seen up close the suffering of cancer patients, not only from their disease but also from treatment effects. His doctoral study is investigating preventative measures to eliminate or reduce the severity of oral mucositis, characterized by swelling, inflammation, and ulceration of the mouth after chemotherapy.

“Just imagine how painful it is,” says Salvador. “Patients are unable to swallow or eat.” Salvador works in an inpatient malignant hematology unit at Princess Margaret Hospital in Toronto and witnessing such effects led him to go back to school. A retrospective study he did for his master’s degree in the US prompted him to continue his research on preventative oral care. This study found mucositis was more severe when oral care began after treatment.

“This changed how we manage mucositis at Princess Margaret; we now advise patients starting chemotherapy to start their mouth care right away, not one or two days later,” says Salvador. The rinse of choice? Water with baking soda, one teaspoon for one cup of water, just the right amount. Too much baking soda meant patients risked burning their mouths or becoming nauseous. Patients found their mucositis more tolerable, but Salvador was not satisfied with the outcomes because there wasn’t enough evidence of efficacy.

His doctoral research is an expanded, multi-site study looking at the use of ice chips and baking soda rinse, and patients’ behavioral change as a predictor of symptom severity. In a hospital pilot study, sucking on ice chips before, during and after chemotherapy, together with the oral rinse, decreased the severity of mucositis, says Salvador. More importantly, it decreased reliance on painkillers and patients were discharged one day earlier. “This may not be statistically significant, but it’s clinically significant,” says Salvador. “It certainly increased patient satisfaction, and decreased hospital costs.”





Cloak of care*

*Palliative care: from Latin *palliare*, to cloak

PhD student Laura Fairley is a palliative home-care nurse for Toronto's street population. But how do you provide end-of-life homecare for the homeless? First you have to find them

By Lucianna Ciccocioppo

The gritty cold streets of Toronto are “home” for a large population, one of the largest in Canada. You may pass by them everyday—their faces rough roadmaps of their arduous outdoor life, their bodies too hollow to hold even hope. Many are living with mental health issues and substance addictions. Add to these a lack of identification, distrust of anyone who basically isn’t “one of them” and sporadic contact with health-care providers, and disease diagnosis occurs much later than the average Canadian. It can also nosedive into a terminal illness quickly as the disease progresses.

This community, however, doesn’t “fit” in the traditional palliative care units of hospitals. The care, then, has to reach out to them.

“Finding people is a big challenge, and continually finding them too,” says Laura Fairley, RN, BScN oT4. “There’s a transitory nature to people’s lives, based on the hostel and emergency shelter system.” This system discharges people during the day, refuses those intoxicated or under the influence of drugs, and may have a limit on duration.

Then there are those who haven’t passed over a doorstep in years, the ones who live in city ravines, under bridges, over sidewalk heat vents. “If people can’t prove they’ve lived in Ontario for at least three months, then identification becomes a problem, and they may have difficulty accessing care. People can deteriorate and die in three months,” says Fairley.

She’s come across these experiences early in her career as a street outreach nurse with St. Michael’s Hospital which specializes in inner city health care and research. “I found it to be really meaningful work; you have to be really creative, really intuitive. Not only do you have your usual nursing responsibilities of care, but you have to think of how to actually provide it, sometimes in bizarre locations.”

Fairley remembers giving someone an injection in the public washrooms of the Eaton Centre, a major shopping mall in downtown Toronto, “because that’s where the person was and that’s where this person wanted to meet me. You have to make it happen in a way that maintains dignity and privacy,” says Fairley.

Outreach nursing can be overwhelming, she says. That’s why she channels her raw emotions through poetry [see “Remember Me” page 38]. At times Fairley had to leave people in difficult situations to go on to find another patient, lingering thoughts of their progressive illness and slow and painful death troubling her.

But that’s something Fairley wants to change. She began a collaborative master’s degree in nursing and women’s studies, and landed a job at Perram House, an end-of-life care Toronto hospice for the homeless



Laura Fairley's PhD research will focus on the unique health-care needs of the homeless with terminal illnesses. "I know when it's time to stay, and time to go."

or underhoused seeking palliative care. Perram serves people with less than six months to live, mostly cancer patients.

The number of people coming to Perram House, and how ill they were, desperate for symptom management, made Fairley think: what's happening out there in the community? Where and how they died, what kind of care they received, who was providing the care and how much—all these questions piqued her interest. As an outstanding master's student, she was fast-tracked mid-way before completion into a doctoral program at the Bloomberg Faculty of Nursing, where she hopes her research will dig up the answers.

Using a method called institutional ethnography, Fairley is investigating how homecare is organized through practices and various texts, such as the Palliative Performance Scale, and how this affects nurses' ability to provide care in homeless populations. Nurses use this scale to assess clients and determine how many hours of nursing care are needed and how many personal support workers to assist them.

"What's imbedded in the scale are assumptions on ability to perform daily activities, such as washing and getting groceries. But for a homeless person who's living on the street, finding somewhere to take a shower involves a whole lot of other steps, which wouldn't be included in the text but would affect measurement outcomes and therefore the type of care," says Fairley.

Her PhD research will focus on the unique health-care needs of the homeless with terminal illnesses, and how the Toronto community deals with such issues. "From there, I'll look at the institution of homecare and how these two subjects perhaps don't mesh well together."

Fellow University of Toronto grad student and street outreach nurse, Laura Hanson, who is currently working on her MN, says the need for such research is urgent. "This is the kind of information you can take to the city or province and say, 'These are the issues homeless people are experiencing in palliative care.' To expand services and get the resources required would be the ultimate goal, and not just for palliative care."

A better understanding of homeless issues means homecare nurses who wish to do street outreach can be better trained. "You need to know where the homeless hang out daily, otherwise you're wasting a lot of time trying to find them." After several unsuccessful attempts, the patient can be discharged from the homecare program due to financial constraints. That means expending more resources to deal with an illness at the very end, instead of treating someone throughout the trajectory of the disease. "You're not playing 'catch-up' but addressing issues as they come up," stresses Fairley.

Her experiences in street outreach will serve her well in connecting with the homeless, developing a rapport with them and learning about their experiences for her research. "I think when you identify yourself as a nurse, there's a level of trust that often isn't there with other professionals. I know when it's time to stay, and time to go." More importantly, she can continue her advocacy work with her clinical nursing expertise, to help link the people she meets to appropriate health-care services.

"I'm trying to accomplish practice change," says Fairley. She wants a change that reorganizes community services for the homeless that deals with end of life—to help give them a dignified death. ♣♣





Life after cancer Life

Unique followup clinics created by Bloomberg Faculty of Nursing alumni are helping to make the transition to 'life after cancer' a little bit easier for survivors

By Lucianna Ciccocioppo

The 'transitional' clinic

At the Hospital for Sick Children in Toronto, the clinics for children suffering from acute lymphoblastic leukemia are extremely busy. About 100 children suffering from ALL, the most common childhood cancer, make the trek to these clinic appointments every week. But children who had completed their treatment were also seen in these clinics for their followup care. They were waiting three, sometimes four hours to be seen by a pediatric oncologist, pediatrician or nurse practitioner, only to be told in a five-minute meeting that "the blood counts are good, you're fine and you can go now," without much time for questions and answers.

Nurse practitioner Sue Zupanec, RN, MN (ACNP) oT4 thought there must be a better way to serve patients off therapy, and their families, during this stressful time. After five years off therapy, these children are seen in the late effects clinic for follow up. But Zupanec found out from colleagues that these patients had missed significant followup diagnostic tests in the meantime. "They hadn't had their echocardiograms done, nor bone mineral density tests," she says. The followup schedule, as outlined by the Children's Oncology Group, was in reality off-schedule. "I saw an opportunity to start the transition to an off-therapy clinic sooner."

She proposed an NP-led transitional clinic and the hospital gave her the green light. In late in 2006, a nurse-led leukemia follow up clinic was started, focusing not only on possible relapse, but also on health and well-being, health education, and monitoring of treatment late effects. Heather Jones RN, BScN gTo, MN (ACNP) oT2, another nurse practitioner who runs the clinic with Zupanec, says the focus is also on "normalization."

"The other goal is to get the families in and out quickly. The children are off treatment and moving on with their lives; we should let them do that." Patients are now seen within 12 minutes of their appointment time, and sessions have been bumped up to 45 minutes. Now there's time to "keep on top of the evaluations that need to be done," says Jones.

The nurses screen for issues such as weight gain and obesity, cardiomyopathy (thickening of the heart muscles), and neurocognitive effects that could affect learning in school.

To fine-tune their assessment skills, Jones and Zupanec developed a screening tool, together with neuropsychologist Dr. Brenda Spiegler, with specific questions to determine possible neurocognitive changes because of the medication, methotrexate. "We know the right questions to ask, and as a result, we've picked up a lot more subtle neurocognitive changes," says Zupanec. These children are referred to neuropsychological screening, where any learning deficits can be identified, their schools

notified, and appropriate assistance or program changes offered. Says Jones: "We're looking for it because we now have the time, and the situation is not deteriorating so that the child is disinterested in school, or worse, failing."

Another effect they look out for is decreased bone mineral density caused by dexamethasone, a steroid used in treatment. There are tests recommended two years off therapy to see if bone mineral density has re-absorbed on its own, says Jones. "We've found a couple of cases with significantly low bone mineral densities, so that allowed us to put the children on calcium and vitamin D supplements. Is this going to decrease the potential for osteoporosis and fractures later on? We don't know, but we can refer them to the osteoporosis clinic early for further monitoring."

Health promotion is a big part of the transitional clinic as well. "If there's a pattern in the child's life for weight gain, we can start to make changes sooner, and track their height and weight statistics," says Zupanec. After five years off therapy, it can be tough to ask an overweight child to start eating healthily and get into an exercise routine.

Their counseling skills extend to parents as well, says Zupanec. "We address anxiety issues. Parental anxiety once the children are off therapy is quite significant." Adds Jones: "It's actually the most stressful time for parents because there's a sense of comfort when children are on chemotherapy every day. But as soon as you stop treatment, parents worry: is it going to come back?" These advanced practice nurses address the issues, particularly if the impact on daily life for parents is great. "We refer parents to counseling, to adjust to life after treatment, and the fear of relapse," says Zupanec.

Zupanec and Jones continue to work in the active clinics as well, and their expertise and new knowledge in areas such as weight maintenance, calcium intake and school issues are shared with their colleagues. "We're promoting preventative interventions through our knowledge transfer to colleagues in our group," says Zupanec.

The success of this unique APN-led transitional clinic has elicited much attention at scientific meetings, while physicians and service providers appreciate the decreasing pressure off their active clinics, and can now focus exclusively on children currently in treatment, says Jones. "They also appreciate our focus on the psychosocial aspects of care...which, in the middle of a busy crazy clinic, is not the first thing you worry about."

But more importantly, says Jones, "They know that we know what we're doing. We know leukemia."



Transitional clinic nurse leaders, Sue Zupanec and Heather Jones:
“We know leukemia.”

The new ‘normal’

Every pain, every ache can prompt an anxious question: is it back? For survivors, the cancer journey is only 50 per cent over when the treatment stops. Trying to get back to “normal” takes up the remainder, says Pamlyn Preston, a breast and kidney cancer survivor from Milton, Ont.

“Your family and friends try to be positive, but nobody really knows if you’re okay,” says Preston, who’s been cancer-free for about seven years. “I still get really nervous when I feel a new pain. But sometimes their optimism is hard to take—they don’t really understand what you’re going through,” she says.

Emotional distress and fear of recurrence are some of the challenges survivors have to face once their therapy is completed because they now have time to think about things, says nurse practitioner Jennifer Wiernikowski, RN, MN (ACNP) oT3, CON (C). Other challenges include combating fatigue, changes in diet and exercise, and cognitive changes. For breast cancer survivors, treatment effects such as hot flashes and menopause symptoms, lymphedema (swelling of the arm where lymph nodes were removed) and painful sex can be disruptive to their lives.

Wiernikowski heard these stories at the Hamilton Health Sciences Juravinski Cancer Centre, and six years ago, proposed a nurse-led followup clinic to help those struggling with the after effects of cancer

therapy. She offered thorough assessments with 20-minute appointments. “These patients are well, but are having complications getting ‘the rubber back on the road.’ So we have a little more time for them. I can still do breast cancer surveillance, and get their mammograms ordered. But I also become the content expert on issues such as lymphedema, fatigue, and cognitive changes. And I can help with their care plans to make the plans a little bit more supportive in nature.”

Wiernikowski went a step further and created specialized symptom-management clinics focusing on menopause after breast cancer and lymphedema. “There’s significant health teaching in the lymphedema clinic, so the patient learns how to manage it, and hopefully it doesn’t worsen.” There’s also substantial support for women “whose sex lives get really derailed,” says Wiernikowski. “Surgery can be disfiguring. These women are dealing with loss of hair, perhaps weight gain and loss of libido. We counsel them. There are some fairly non-invasive medical and non-medical interventions one can try. I also have a number of local specialists to whom I can refer patients when nursing interventions are not effective. We have a sexual medicine clinic and a local physiotherapist who has a great deal of expertise working with cancer patients, so they are a great resource.”

She’s currently the chief of nursing practice at the JCC, but still manages to dedicate one half-day a week to attend to breast cancer



Jennifer Wiernikowski and Margaret Forbes: nursing's answer to the growing number of breast cancer survivors transitioning to their new 'normal.'

patients in the clinics. She's pleased to see the clinic grow "more robust" with Margaret Forbes, RN, CON (C) who took over the initiative, and is currently an online master's student (ACNP) at the Bloomberg Faculty of Nursing. Forbes has partnered with a general practitioner in oncology (a family physician with specialized oncology training) for the well followup clinic, and continues to lead the managing menopause and lymphedema clinics. Some of the stories she hears are more poignant.

"A lot a younger women are concerned about what the future holds for their family, and their children. They worry if they have a genetic predisposition to breast cancer," says Forbes.

And with the increasing number of cancer survivors, Forbes says the importance of these followup clinics cannot be stressed enough. "The patients declare them to be a vital part of their survivorship," she says. Not only do these APN-led clinics alleviate overbooking at the oncologists' visits, but they also give a sense of empowerment to survivors. "People tell me 'I now have the information to do x, y or z and get on with my life.'"

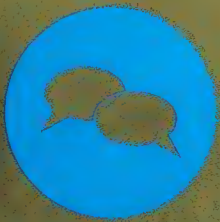
The oncology nurse has 19 years of clinical knowledge and expertise behind her to examine and assess patients for possible recurrence, and assess them in a broader psychosocial context as well. "Unfortunately, a routine followup appointment with an oncologist doesn't allow

enough time to delve into the complexities of survivorship issues. What Jennifer Wiernikowski and I have managed to do is carve out the role to be the content experts in the field. So we can give the latest information on managing lymphedema or menopause effects not only to our patients, but also to our team," says Forbes.

Their health educator roles extend outside the cancer centre. Forbes is collaborating with the local YWCA on "Encore," a rehabilitation program which combines land and water exercises for breast cancer survivors, and is also an informal support group. Wiernikowski was a founding organizer in 2001 of an annual Life After Breast Cancer conference for survivors to hear the latest in managing their treatment effects, physical and psychosocial.

It's nursing's answer to the questions arising from the growing number of survivors making the transition to their "new normal." It's a streamlining of services to address the ballooning followup practices oncologists are struggling to maintain on limited time.

"It means breast cancer survivors who are having trouble managing long term side effects will be more successful in managing their own health—coping, living and moving beyond their breast cancer therapy, to engage in their normal activities. It definitely takes an interdisciplinary team to make all this happen, but I do believe nursing contributes a great deal to that," says Wiernikowski. ♡



Q&A



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Q&A with Dr. Verna Huffman Splane

Dip. Public Health Nursing, 3T9, DSc. 0T7

Nurse, educator, consultant, author. *Pulse* talks to Canada's first principal nursing officer about her career of 70 years

By Lucianna Ciccocioppo



Pulse: What was life like for a nurse in 1939 when you first graduated from the University of Toronto?

VHS: In 1939 we were of course caught up in the declaration of the Second World War. As new graduates, we were concerned for our country, and as nurses, whether we were going to sign up for military service or going ahead with what we had been preparing for. I had no choice because I went to the University of Toronto with the assistance of the Victoria Order of Nurses (VON), which committed me to the next two years of service. It was a time of uneasiness about the future, but in general, the nursing profession was ready to serve either at home or abroad.

Pulse: When you mention the word ‘nurse’ today, you could be referring to a registered nurse, nurse practitioner or clinical nurse specialist, a research scientist or executive or government leader. What do you think about how the role of nurses has expanded from the last century to this one?

VHS: The expansion of roles and the development of new ones in the past century is without precedent in this country. In my view, the fundamental change that led to many others was the movement of nursing education from hospital schools to the public system of education—the university—as outlined in the Weir Report in the 1930s. That transition and the introduction of the national health insurance system in Canada have opened doors for nurses into areas of leadership previously unknown, nationally and internationally. It was a demanding and exciting time for nurses exploring new paths of service and professional relationships.

Pulse: Your international work in nursing began in 1959 with the World Health Organization. What does ‘global nursing’ mean to you and why is it important?

VHS: Even before I worked with the WHO, I believed nurses should be taught from the beginning that they are part of a global profession. We know that what happens in the health field in one country has a potential effect on other countries. I learned much in the WHO to support that conviction, as well as in my two vice-presidential terms with the International Council of Nurses. The ICN deals with global issues based on direct reports from the far corners of the world. Canadian nurses already have a distinguished record of working in these two international organizations, and since the need for service is not limited to one country, as shown repeatedly today, we should continue to prepare nurses to serve wherever the need is—at home or abroad.

Pulse: Tell us about your international study of chief nursing officers in the ministries of health in 50 countries. What questions were you asking and what did you find out?

VHS: When I retired in 1985 my husband asked me: ‘What are you going to do now?’ I said I’d like to follow up on a movement that started with the WHO, which urged the promotion of a senior nursing position in governments to be involved in shaping national health-care policies. I had been involved in many countries in promoting a chief nurse officer position and wanted to see what had happened to that movement. Where did it still exist? How had it been developed? What difference had it made to health-care systems? My husband, Richard Splane, an international research scholar in social policy and history, offered to help me. And so began our independent study that took

us into 50 countries for interviews with all the nurses who had held that position. We were fortunate that some of the first chief nurses were still around. The study took eight years to complete, in combination with our other professional commitments, and we had great support for the project from the WHO. It’s all described in our book, published in 1994, which has become the ‘bible’ in major regional offices of the WHO in helping countries develop chief nursing positions. It was one of the most interesting projects of my whole career.

Pulse: What was its impact?

VHS: I haven’t been into any of the countries in a professional capacity in the last 10 years, but we still hear from people who are currently in these positions and who are convinced that nurses have a role to play in shaping national health policy. The impact of the movement is reflected in the World Health Assembly, where many chief nurses are included on their country’s delegation and records show an increasingly significant contribution in their country’s participation.

Pulse: What does the future hold for nursing?

VHS: I think nursing has a great future. The quality of education available to nurses today with strong international leadership, the constant demographic changes of this new century, the public pressure for changes to the health-care system, new inter-professional research activities in government and universities, and the maturing of the organized nursing profession itself—all of these things speak to an open door to the future for nursing never before possible.

Pulse: Any words of advice to the graduating Class of 2009?

VHS: Embrace change. Sustain engagement in community development in its broadest sense. Add continuously to your unique educational skills and knowledge in applying fresh enthusiasm and bright young ideas to shape a better world in your century. From my experience, it may be hard work but it can be fun!

Pulse: What’s your favourite technological gadget?

VHS: That’s one area where I’m not very literate. I use email and word processing, and occasionally the Internet. But I could not work out my ticket to go to Timbuktu, for instance. So there are many things about the system I don’t understand. But yesterday, I did look up something on the International Council of Nurses on the Internet and that prompted me to think maybe it’s time for me to take another course in communications.

Pulse: Any plans to ‘retire’ again soon?

VHS: [laughs] No.

Dr. Verna Splane resides in Vancouver with her husband. She has an illustrious list of accolades, awards and degrees, among them a bachelor of science and master of public health and several honorary doctorates, the Order of Canada, the Queen’s Silver Jubilee Medal, the Red Cross’ Distinguished Service Award, and the Canadian Nurses’ Association’s Jeanne Mance Award for Outstanding Contribution to Nursing. She still remains in contact with her friend from Class of 3T9, Catherine Maddaford, of Toronto.



The dawn of the 'de Souza nurse'

As the number of cancer survivors continues to climb, the oncology-nurse workforce is facing a shortage. But the de Souza Institute is trying to change that

By Dr. Mary Jane Esplen, RN, BScN 8T5, MScN 9T1, PhD 9T7, director, de Souza Institute, associate professor, Lawrence S. Bloomberg Faculty of Nursing

The oncology-nurse workforce is facing a daunting challenge. That's because cancer is a leading cause of premature death in Ontario and the province's number one health problem. Someone is diagnosed with cancer every eight minutes and, according to Cancer Care Ontario, 38 per cent of women and 41 per cent of men will develop cancer in their lifetime. If current predictions remain unchanged, the number of diagnosed cancers in Ontario will rise to 91,000 in 2020.

That's a lot of cancer cases requiring much needed cancer care. But only about one per cent of registered nurses in Canada, or 2975 RNs out of more than 250,000, are employed in an oncology-related field. CNA also found in 2007 only 764 RNs in Ontario hold CNA oncology certification. This number has since dropped at the provincial and national levels, due to changes in specialization or retirement. And there are more retirements to come. Compared to other fields of nursing, the oncology-nursing attrition rate is higher, most likely due to the emotional demands associated with caring for patients with cancer and their

families, and in managing the complexities in oncology practice. All this suggests a vast shortage of oncology nurses is on the horizon at a time when cancer care is more challenging than ever.

Cancer is now viewed as a chronic disease, since more effective treatments have resulted in individuals living longer. This gives rise to complex survivorship issues, which often have a significant impact on quality of life. Studies have shown the psychosocial and emotional distress associated with a cancer diagnosis, often experienced as depression or other adjustment difficulties, is a significant problem for up to 50 per cent of all cancer patients. It can affect family too, and can occur along the whole continuum of cancer.

In addition, recent genetic advances have led to new approaches to the assessment of cancer risk and preventive interventions for healthy individuals. Genetic treatments and prevention strategies will be more fully integrated into clinical medicine over the coming decades. Biomedical advances have also increased our understanding of genetic differences in pharmacological sensitivity between individuals, leading to the tailoring of medications based on inherited characteristics. New conceptualizations of palliative care have resulted in calls for further research and innovative approaches to care. And with reductions in health-care resources in Canada, cancer care is increasingly being moved into community-based settings and homecare.

Oncology nurses play a vital role throughout the cancer continuum of prevention, screening, diagnosis, treatment, survivorship and palliation. They fulfill a wide range of important patient-centered directives. They deliver state-of-the-art treatment protocols, as well as respond to the psychological, spiritual and cultural needs of patients and their families. As academics, they educate future generations of nurses. As researchers, they are responsible for identifying knowledge gaps, conducting research programs and translating knowledge into practice.

Are we preparing our nursing students to address all of these on-going and rapidly emerging new knowledge gaps? Are we providing opportunities to address challenges and join the growing initiatives occurring in the cancer field? And, are we effectively addressing the emotional burden of cancer that often results in attrition among nurses?

I would argue the answer to these questions is “No.”

It's true we have invested in expanding our undergraduate and graduate academic programs, mainly through general or expertise areas such as the adult medical or pediatric programs. While we have known for some time there are few academics within the field of oncology, we continue to have a huge shortage of well-prepared academics to lead the way in stimulating or setting up new curriculum to address the complexities of cancer care and research. There are also fewer clinician-scientists to generate the required knowledge that can be integrated into practice to support the translation of biomedical research and treatments.

While there are occasional continuing educational opportunities for nurses encountering oncology patients and families in their practices, these are not often based on the most recent evidence, on urgent knowledge gaps or on the vast number of emerging technologies or changes occurring in the field. Little opportunity exists for current nurses, students or new graduates to fully engage in interprofessional teams, to reflect upon interprofessional practice models and how best to work within them. Direct and immersed experiences are the best approach to gain the required assertiveness, self-efficacy and communication skills to work within or lead such teams.

Standards and guidelines now exist, or continue to be developed to

guide nursing care for patients with cancer and their families, through such organization as the Canadian Association of Nursing in Oncology and the Canadian Association of Psychosocial Oncology. These standards, however, have yet to be translated effectively into care.

But there is some good news. It is currently an exciting time in Canada with the establishment of the Canadian Partnership Against Cancer, a national strategy for cancer control which, for the first time, prioritizes cancer care. This is an excellent time for our discipline to participate as leaders to improve cancer care, to develop and adopt guidelines and standards into practice, and to use new resources to facilitate knowledge translation and access. CPAC is counting on us to address practice issues and create new opportunities for educational programs and strategies to address the complexities and challenges we face.

More importantly, the increased awareness of attrition in cancer care has forced leaders to make “taking care of the self”—an often neglected aspect of all nursing—a priority. The current high attrition rate, due to the challenges and associated burnout in the field of oncology, needs to be addressed. Nurses require self-care support for issues such as stress, grief and loss. They require career planning opportunities for advanced levels of practice to address gaps in leadership.

Addressing all of the above requires a variety of strategies. We need more oncology nurses, which requires active recruitment and creative planning to keep them there. We need more specialized training, such as CNA oncology certification and specialized programs of certification, such as chemotherapy delivery. General practice nurses need more knowledge and expertise to care for oncology patients and their families, as they will increasingly encounter cancer cases. Graduate programs need to expand to provide advanced knowledge specific to oncology and prepare the needed academics, educators and researchers to generate oncology research relevant to practice.

Leading the way to help address these challenges is Ontario's de Souza Institute, a knowledge-transfer centre for oncology nursing based in Toronto. Established in May 2008 with a \$15 million funding boost from the nursing secretariat of the Ministry of Health and Long-Term Care, the institute is a partnership with the provincial government and Princess Margaret Hospital, University Health Network (UHN) and Cancer Care Ontario, with University of Toronto and McMaster University as steering committee members.

Over the next five years, expect a state-of-the-art institute for educating oncology nurses in Ontario, including courses to support the CNA exam certification, and “train-the-trainer” programs to create “de Souza experts.” These oncology experts will have the professional capacity, knowledge and skill to provide the care that matters most to oncology patients and their families. The de Souza Institute will facilitate graduate education and encourage specialized graduate programs. Research fellowships will support new researchers and clinician-scientists. Clinical fellowships will support new graduates and current practicing clinicians. Expect a highly trained “de Souza nurse” in all sectors from primary and acute care to long term care. Expect a new kind of oncology nurse, uniquely poised to address many of the challenges along the cancer journey for patients, their families and all Canadians.

Dr. Espen is a CIHR clinician-scientist, and heads the psychosocial and psychotherapy research in cancer genetics program at University Health Network. She is also an associate professor in the Faculty of Medicine's department of psychiatry at University of Toronto.

Cressy award winners

Gordon Cressy Student Leadership Awards were established in 1994 to recognize undergraduate or graduate students who have made outstanding extracurricular contributions to their college, faculty or school, or to the university as a whole. The following Lawrence S. Bloomberg Faculty of Nursing students are 2009 recipients: Shawna Ardley, Hilary Hall, Scott Jones, Jennifer Lapum, Doris Leung, Maria Parzanese. Congratulations on your hard work and admirable contributions to the Bloomberg Faculty of Nursing and the University of Toronto!

Getting to know you

The first of hopefully many “Dinner with 12 Strangers” series kicked off on Feb. 23, 2009. Students, alumni and faculty participated in the casual social networking event, which took place in the home of alumni host Joyce Rankin, MN oT2, MBA oT5, and was assisted by co-host Cecile Raymond, RN, MHS oT4. Guests enjoyed a home-cooked meal of lasagna and salads, and a lively discussion on a variety of topics involved current students, alumni from a wide range of graduating years and faculty member Krista Keilty, assistant professor and director of the post-masters NP diploma. “It was great fun, and a chance to make 12 new friends, from all areas of nursing,” says Rankin. “I would do it again, and encourage others to try it.” Her co-host agrees. “Everyone had great stories to share about their education and work experience. It was an excellent networking opportunity,” says Raymond. Grad student Billie Hilborn, who is in her third year of the collaborative PhD program with the Joint Centre for Bioethics, appreciated the informal mix of students, faculty and alumni. “It was relaxed and open.” The adventurous guests came as strangers but left with new friends, valuable connections and a strengthened sense of the U of T community. View photos on our Web site: bloomberg.nursing.utoronto.ca/alumni/gallery/dinnerwith12strangers.htm. For more information on upcoming dinners, please contact 416-946-7097 or development.nursing@utoronto.ca.

Find us on Facebook

Want more nursing friends, or looking to stay in touch with old ones? Look for the officially sanctioned Lawrence S. Bloomberg Faculty of Nursing Alumni group on Facebook. Nursing students and alumni are welcome to join, and stay in touch, learn about lectures, events and other Faculty or alumni news.

facebook

Countdown to 2010

It's our birthday next year! The Bloomberg Faculty of Nursing turns 90, and we're getting ready to celebrate. Tune in for exciting events for students, faculty, alumni and friends and a special edition of *Pulse* in Fall 2010. Have ideas for celebrating? Please forward them to development.nursing@utoronto.ca.

Is there a poet in you? Announcing *Pulse's* poetry contest

Pulse magazine wants to hear from the poet in you. Submissions to our “Expressions” page are welcome, and one winner for each issue will be selected for publication. Show us the art of nursing through poetry; we'd love to hear from you! Please email pulse.magazine@utoronto.ca with your submission. Deadline is July 15, 2009.

New professional development centre for ‘thought leaders’

Dr. Judy Watt-Watson, RN, BScN 6T7, MScN 8T4, PhD 9T7 wants health-care professionals to turn to the Centre for Advanced Studies in Professional Practice, U of T, for the most advanced information on the complexities of patient care. “I want to provide opportunities for people to learn about the latest thinking, evidence and strategies that they can apply to their practice when they go back to work on Monday morning,” says the head of CARPP.

CARPP is the newest centre offering health-care practitioners the latest information to enhance their careers, and further their clinical leadership skills with some of the best minds in health care today.

“This centre aims to be different. We're focusing on advanced studies on the challenges of patient care, and we have a wonderful community of experts—clinicians and scholars—who are leaders in these practice areas,” says Watt-Watson. “Health care is very dynamic, with considerable changes happening. It's important for us to continually update our knowledge and expertise with the latest thinking.”

Watt-Watson is surveying leaders at hospitals across Toronto and the GTA to hear where the knowledge gaps and challenges are for health-care practitioners across the board. And she plans for CARPP to step in and address the issues with clinical institutes, courses on preparatory exams, and advanced programs. The centre is targeting those with some clinical experience who want to advance their practice knowledge and skills. “It's for ‘thought leaders’—and for those who want to be,” she says.

Upcoming programs include:

Institute: Complex Care Management in Cardiac, Critical Care and Neurological Settings, May 1, 8, 29, 2009

Institute: Innovations in Palliative Care, June 5–7, 2009

Canadian RN Registration Exam Preparation, Sept. 12–13, 2009

For more information visit:

bloomberg.nursing.utoronto.ca/CASPP.htm

Pulse wants to hear from you: Do you come from a family of nurses? Are you, or do you know of, a nurse married to an engineer? These are some of the future ideas we're working on, and we'd be delighted to have your input. The editorial staff of *Pulse* encourages readers to send in their suggestions and story ideas to: pulse.magazine@utoronto.ca. Next issue features **community nursing**.

Shopping night for nursing alumni at TYPE Books!

Here’s a great way to add to your library while having fun with fellow alumni at the oh-so-funky TYPE Books, Toronto’s hottest book and gift store. U of T nursing alumni will **shop at a 15% discount** for the evening and enjoy light refreshments and hors’ d’oeuvres. Get fun, summer reads, just in time for Mother’s Day, too! For information and to RSVP, call: 416-946-7097 or email: development.nursing@utoronto.ca

Date: May 7, 2009
Time: 6 – 8 pm
Location: TYPE Books, 883 Queen St. West, west of Bathurst St.

Nursing Week 2009

The Lawrence S. Bloomberg Faculty of Nursing invites you to join us in celebrating National Nursing Week, May 11 – 17, 2009 with a special lecture and research exhibition on:

Date: Tuesday, May 12, 2009
Exhibition: 5:30 – 7 pm
Lecture: 7 – 8 pm
Location: Lawrence S. Bloomberg Faculty of Nursing
155 College St., Toronto

Title: Improving Women’s Health While Reducing Inequities: Challenges and Opportunities.
By: Arlene Bierman, MD, MS, associate professor, Bloomberg Faculty of Nursing, cross-appointed with Department of Health Policy, Management and Evaluation and Department of Medicine, Division of Geriatrics and General Internal Medicine, Faculty of Medicine, University of Toronto.

Dr. Bierman, MD, MS, FRCPC, general internist, geriatrician and health-services researcher is the inaugural holder of the OWHC chair in women’s health at the Bloomberg Faculty of Nursing at the University of Toronto. She is a senior scientist in the Li Ka Shing Knowledge Institute at St. Michael’s Hospital and adjunct scientist at the Institute for the Evaluative Clinical Sciences (ICES). Dr. Bierman serves as a member of the Ontario Health Quality Council, chair of its Performance Measurement Advisory Board, on the Board of Directors for the National Centre of Excellence program at the National Initiative to Improve Care for the Elderly (NICE). Her research focuses on improving access, quality, and outcomes of care for older adults with chronic illness, with a special focus on inequities in health and health care.

For further information, please call: 416-946-7097 or e-mail: development.nursing@utoronto.ca

Celebration in honour of convocation

A Convocation breakfast celebration will be held on June 9, 2009, 7:30 am to 8:30 am for MN, PhD and NP students and their families before the 10:00 am Convocation ceremony. The graduating class from November 2008 is also invited to celebrate Convocation with their families at this breakfast event. For further information or to RSVP, please call 416-946-7097.

Spring reunion

Join classmates, friends and colleagues at the Lawrence S. Bloomberg Faculty of Nursing Alumni Breakfast.

Date: Saturday, May 30, 2009
Location: University of Toronto, Health Sciences Building
6th Floor Auditorium, 155 College Street
Cost: Free
Honoured years: Classes ending in ‘4’ or ‘9’; all years are welcome!

9:00 AM – Annual Complimentary Buffet Breakfast
10:30 AM – Distinguished Alumni Awards Presentation
11:30 AM – Clinical Simulation Learning Lab Tour

For more information, or to RSVP (acceptances only) by May 15, 2009, please contact:
Bloomberg Faculty of Nursing
Telephone: 416-946-7097
E-mail: development.nursing@utoronto.ca

Want to contact old friends?

For assistance in contacting your fellow alumni, please do not hesitate to call us at: 416-946-7097 or at development.nursing@utoronto.ca.

Dinner with 12 strangers

It’s a simple and fun idea: local alumni host dinners in their own homes for students, faculty and fellow alumni in an effort to make U of T a smaller, friendlier place. An alumnus from the Faculty of Nursing will host an evening of good food and good conversation. The program offers participants an opportunity to make new friends, valuable connections and to strengthen the U of T community. Dinners will take place between March – May and on a weeknight (excluding Fridays) from approximately 7 – 9pm. If this sounds like an event you may be interested in, please contact our Alumni Relations Office at 416-946-7097 or development.nursing@utoronto.ca.

Alumni lifelong learning series

This is a new program exclusively for our alumni and is hosted over lunch. Upcoming topics and speakers include:

Oct. 23, 2009 Dr. Linda McGillis Hall: *Gone south: Canadian nurse migration to the US*
Oct. 30, 2009 Dr. Denise Gastaldo: *Undocumented workers’ health issues in Ontario: Working conditions and access to health care*
Nov. 6, 2009 Dr. Louise Rose: *Hot topics in critical care*



For more information on these events, view bloomberg.nursing.utoronto.ca/alumni/newsevents.htm

From the Class of:

1955

Organ, Barbara: In 1950, my real goal was to become a student nurse at the Hospital for Sick Children, but the entrance age was 18 and I was too young. So I decided to spend a year at U of T while waiting and the School of Nursing sounded like a good place to do that. Kathleen Russell was the dean then and her philosophy of a new way to educate nurses appealed to me. I stayed, worked hard, and finally graduated in 1955. For the next 35 years, I worked in labour and delivery, teaching prenatal care and child welfare. After some courses and study, I spent the next 14 years working in occupational health, community nurse supervision, obstetrics clinical instruction, working with a physician in the gynecological care of disabled young women, teaching sexuality and sexual health to these same young women, and finally, working as a care manager at the Community Care Access Centre. At 65, I “retired” from nursing and to my delight, what seemed like an ending turned out to be the beginning of one of the most exciting parts of my life! In the last 10 years, I worked in a failure-to-thrive unit in a hospital in Tutova, Romania, “mothering” and feeding babies condemned to die without intervention; I helped to set up a program to increase their survival rates. I worked in the former Soviet Union with a group of Canadian doctors, providing outreach health care and teaching in six impoverished communities in Belarus. I helped to set up an “Out of the Cold” program in my synagogue, managing and teaching health and safety to the guests and volunteers, advocating for the guests and the program, and listening when the need arose. I taught knitting on a 10-day cruise through our eastern provinces and down to Boston. I now need to use a cane or walker to get around, so I have had to quiet down a bit and am now “working” in the triage section of a hospital emergency department. The salary in these past 10 years has been amazing! Though none of it has been in money, it has fueled my body and my soul. This is the life and inspiration that was given to me at the School of Nursing when I was young. I feel so very fortunate and grateful to have been able to carry it and run with it. barbaraorgan@rogers.com

1956

Peters, Pat (nee Woods): Upon graduating, I moved to Prince Rupert and worked in acute medicine/ICU. Quickly I felt the need to get more advanced training and moved to Victoria, BC. Little did I know I was moving to “paradise.” I worked in open heart ICU, became head nurse after 12 months, then did a year of research for the surgeons (a five-year retrospective study). I moved to another Victoria hospital, then was accepted at McGill University for my master’s degree. Unfortunately after 6 months, my two-year plan was being stretched, due to a lack of acceptance of clinical research. Money was short as I was not bilingual and couldn’t be employed as a nurse. I headed back to the coast, and was head nurse for 12 years until the role was phased out. I transferred to community nursing and home-support management, then back to discharge planner in the hospitals. I am now semi-retired and living near a lake and working part-time. I love it and plan to retire in three years unless there’s incentive to stay past 60. papeters@shaw.ca

1972

Drummond, Jane: As you can see from the listed Web sites, I have been pretty busy since my BScN graduation. I am vice-provost of the health science council at the University of Alberta. I have a fairly large research program where I am principal investigator on “Families First Edmonton,” and my hobby is fiber art. jane.drummond@ualberta.ca

Health Science Council

www.healthscience.ualberta.ca

Nursing Research Program

www.uofaweb.ualberta.ca/nursing/jdrummond.cfm

Families First Edmonton

www.familiesfirstedmonton.ualberta.ca

The Buddha Dharma: The Four Noble Truths

www.med.ualberta.ca/education/documents/thebuddhadharmapdf.pdf

1973

West, Bonnie (nee Millen): I graduated in 1973 with my BScN and did public health nursing for several years. I came home to raise a family and be part of an active farm north of Toronto. Through community volunteer work with Federated Women’s Institutes of Ontario (a non-profit charitable group working with rural women), I discovered the company “Jeunique International” which carries supportive bras and undergarments. I now have my own direct-selling business as a certified custom-bra fitter and have been doing bra clinics for almost seven years, with referrals from health professionals such as doctors, physiotherapists and chiropractors, as well as the general public. The garments help women look and feel better by relieving pressure on their shoulders, improving posture and lymphatic drainage. As a result, I still feel involved with helping women improve their health. lbwest@bconnex.net

1976

Finlay, Dorothy Ann: As a wife and a mother of three young children, I graduated with a BScN from UofT in 1976. Following graduation, I began a very interesting and busy career in nursing education at the Wellesley Hospital in Toronto. After about eight years, I held a similar position at St. Michael’s Hospital as a facilitator of the nursing process project. My final position at St. Michael’s (where I received my basic RN education) was coordinator of quality assurance for the hospital-wide program. That was a unique and challenging position which I thoroughly enjoyed for approximately six years. I am grateful my nursing degree enabled me and my husband to finance our three daughters’ university education and gave me the opportunity to network with so many fine nursing colleagues. I am now retired from the nursing profession, am 69 and work at Woodbine Racetrack cooling out the thoroughbreds after their workout—a fun job that allows me relaxation with the beautiful horses!

Pryce, Cathy: I started in 1976 as a newly minted staff nurse on a medical surgical unit in Toronto, and after an amazing journey that has included lots of public health, some acute care, some primary care, lots of administration and more than a little support from colleagues, I find myself the senior vice-president of mental health and addiction for Alberta Health Services. I honestly never imagined the career of possibilities that nursing would offer. It has been, and continues to be, a great ride!

1980

Dickson, Joyce: In 1981, I began working at Whitby Psychiatric Hospital in quality assurance, then in-service education. I moved to the Lindsay Outreach Clinic, until 1988. I had a counseling practice from 1993 to 2007. Currently, I am a monitor for the College of Physicians and Surgeons for a physician who has been charged and is awaiting trial for sexual charges. I have been trying to keep track of the Class of 6T6. You can contact me through development.nursing@utoronto.ca

2001

Sangha, Gurgit: After completing my BScN at U of T in 2001, I began my career at the Hospital for Sick Children in the hematology/oncology program as a staff nurse on the inpatient oncology unit. During my time on the inpatient unit, I had the privilege of representing my colleagues on the hospital-wide RN council and continued my involvement with the RNAO as the regional representative for region 6. I began my MN (Clinical Stream) in 2004 on a part-time basis, while continuing to work full-time. Also in 2004, I left the inpatient unit to cover a maternity leave in the Interlink Community Cancer Nursing, pediatric program. In 2006, I began working as a project manager through the centre for nursing at the Hospital for Sick Children, leading the implementation of best practice guidelines. I completed my MN in June 2008 and began my current role as a clinical nurse specialist in palliative and bereavement care at Sick Kids.

2002

Taylor, Louise: Since graduation, I have been lucky enough to work with the cystic fibrosis service, respiratory medicine division, at the Hospital for Sick Children for the last 24 years. I graduated from the University of Western Ontario in 1982 with my undergraduate nursing degree. I returned to school to do my MN (NP-Pediatric) program at U of T part time and graduated in 2002. I was training to take over the role of the nurse practitioner for the CF patients that we follow, a natural transition from being the clinic nurse for all those years. I love having the added responsibilities of taking on patients within our service. My specialty is caring for the newly diagnosed patients and their families, as well as working with the difficult teens, the struggling families and finally the palliative children. I also take great pleasure in teaching at all levels—from the undergrad nursing students at U of T, to individual families or teenagers, to the parents and families who attend our annual teaching day. I wrote and passed the NP exams in spring 2008, so I am officially a nurse practitioner in pediatrics. And I am looking forward to many more years in this position, as I have just taken on the newborn screening program with our genetics division. I help run a community support group for families of children with CF in the west end of Toronto. There are still a lot of challenges within my practice, and no time to be bored.

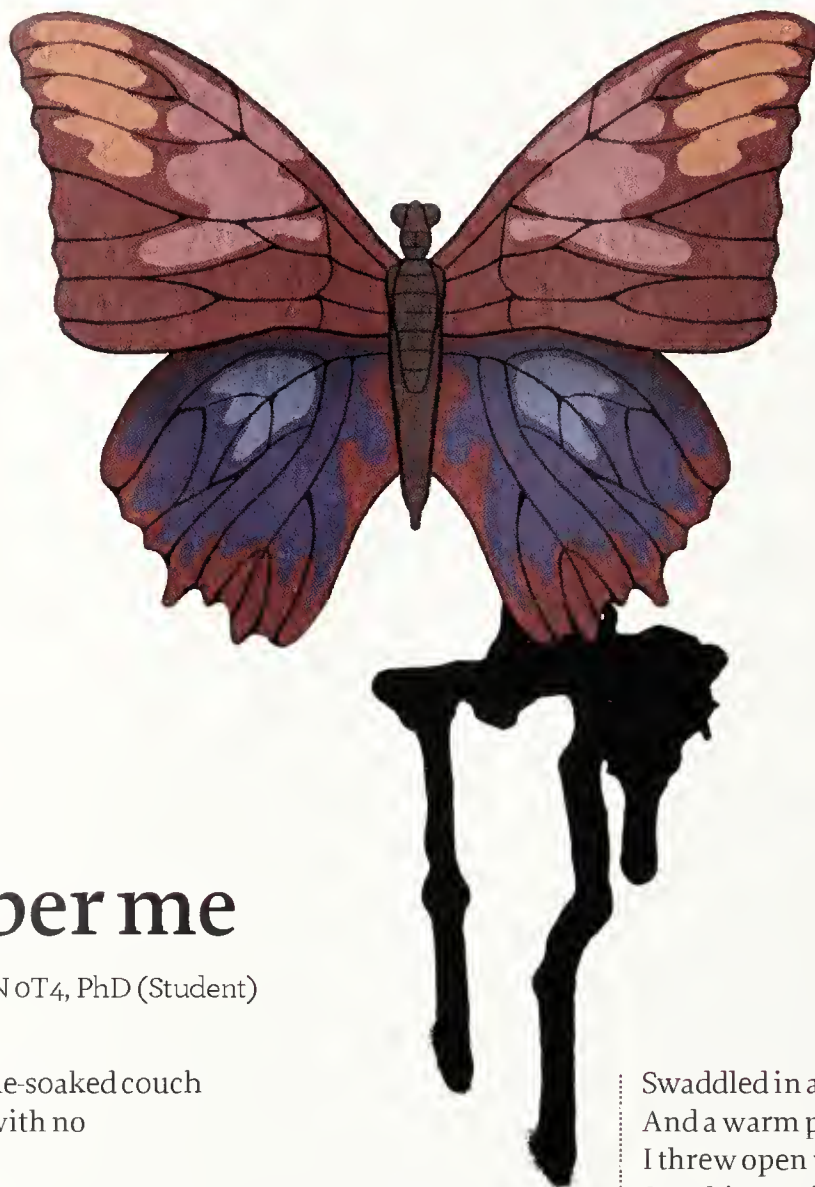
Van Sickle, Marie (nee Robinson): I graduated in 2002 and moved to Hamilton, Ont. I worked in the intermediate cardiac care unit at Hamilton General Hospital for two years. I completed advanced cardiac life support certification, started the critical care nursing certificate, and obtained a position in the coronary care unit at Hamilton General. I worked there for six months before getting married and moving with my husband to British Columbia. I obtained a full-time position at Matsqui-Sumas-Abbotsford (MSA) General Hospital in the ICU and MSA sponsored me to take the BCIT critical care nursing course. Upon completion, I worked in the ICU for one year before taking a maternity leave. Once my maternity leave was completed, I did not return to work as we were moving to Vancouver Island due to my husband's employment opportunity. I just gave birth to my second child in November and will be enjoying this next year with both children at home.

2005

Albrecht, Anya S.: Upon graduation in 2005, I began my career at Akron Children's Hospital Emergency Department in Ohio. I then went on to take a similar position with Summit County Children's Services Medical Clinic, where I helped with the operations of the clinic and direct patient care for children who entered the custody of the county. In 2007, I decided my interests lay in medical operations and finance. I began graduate school for accounting and finance at the University of Akron and will be graduating this semester with my MS in accounting. I am currently employed as a financial analyst with Summa Health System Hospitals (SHSH) in Summit County, OH. SHSH is a five hospital non-profit system that provides a breadth of care. My role is focused on financial modeling during the contracting process with insurance organizations throughout the country. While I am no longer employed directly in patient care, the knowledge and training that I developed during my time at U of T, and while I practiced as an RN, directly impact the financial decisions I make today. albrechta@summahealthnetwork.org

Ng, Christina: Two weeks after I wrote my RN exam, I went to Thailand to volunteer for about five months. I travelled to Malaysia, Hong Kong and Beijing as well. Upon my return, I had two interviews at the Hospital for Sick Children and landed a job on 4D working with children who had cardiac defects. After that, I obtained a job with the Canadian Mental Health Association and loved it. I was a nurse case manager working in the community with youth who had either bipolar or schizoaffective disorders. I wanted to brush up on my nursing clinical skills again so I went to Casey House where I also worked in the community, but this time with people living with HIV/AIDS. That was also a challenging experience. Currently I am working for the Region of Peel as a public health nurse in the communicable disease department. I enjoy the work I do, investigating various reportable diseases. Hopefully, I'll be able to use this when I'm working overseas. Being a nurse has allowed me to work in so many different areas and for that I am thankful. I have had a chance to be involved in people's lives in such a personal way that it would not have happened in such a way in another field. c_ng19@yahoo.ca

For more career notes, please view:
bloomberg.nursing.utoronto.ca/alumni/stayingintouch.htm



Remember me

By Laura Fairley RN, BScN OT4, PhD (Student)

They found you on a urine-soaked couch
Under a cracked ceiling with no
Light.
Whispering breath,
Bugs scavenging
Your withered body.
Warehoused in an abandoned warehouse
Abandoned.

When they brought you to me
I thought you were already dead...
A skeletal corpse on a heap of starched linens
But when I gathered you in my arms
You opened your jaundiced eyes
And cried.

I gently cut off your jeans
Knees crusted in the dried salt of
December's slush
And peeled off your shirt
Uncovering the canvas of your secret shames
And scars.

Drenched in a tide of liquid feces,
Your raw flesh sloughed off in my hands.
The stench was overwhelming.
I knelt down next to the bed and slowly bathed you,
Soothing the deep burns found on your fingertips
And washing the mats out of your long blonde curly hair.

Swaddled in a clean cotton nightgown
And a warm purple quilt
I threw open the shutters of your window to let in the
Sunshine and the crisp blue Morning Sky.

You asked me where the hell you were.

You are home...

I spent the day perched on the side of your bed
Feeding you mouthfuls of
Rum and raisin ice cream,
And tending to the butterfly in your thigh.

You touched my cheek and asked me in a raspy voice
Not to forget you...
Gave me a watery, gummy smile.
The cadence of your heart changed.
Six hours later,
It fell silent.

Etched in my soul,
You're why I still find myself here. ♪

Lawrence S. Bloomberg
Faculty of Nursing Presents:

HPE 2009 Conference

Health Professions Education
Global Best Practices in Simulation
May 21 to 23, 2009
Hart House, University of Toronto

Conference Themes

- Simulation, virtual simulation and e-learning
- Assessment of simulation-based learning
- Technology-supported learning
- Inter-professional education
- Student and educator experience with simulation
- Monitoring competencies through simulation
- Other educational innovations

Conference Objectives

The overarching Conference objective is to bring together researchers, educators, practitioners, decision-makers, and students to develop synchronous efforts in setting best-practice standards for simulation-augmented health professions education.

The Conference will strive to foster a positive environment for an exchange of ideas, presentation of research findings and sharing of strategies for implementation of simulation in education. In addition, the Conference aims to promote formation of collaborative research networks at both international and national levels.

We anticipate that with your continuous support the Conference will grow to an annual international event with focus on health professions education.

Featured Speakers

Patricia E. Benner R.N., Ph.D., FAAN
Professor Emerita, Department of Social and Behavioral Sciences and Department of Physiological Nursing

Brian David Hodges MD, PhD, FRCPC
Director, University of Toronto Wilson Donald R. Wilson Centre for Research in Education at the University Health Network

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